

EUREOS ANNUAL REPORT 2021/22

Alfredo Lucendo, President

Arjan Bredenoord, Past-President

ADDRESS

Alfredo Lucendo

Hospital General de Tomelloso, Spain

Committee's Office

www.eureos.online

info.eureos@gmail.com

www.centerview.ch

ABOUT EUREOS

EUREOS is the meeting point for clinicians and researchers to share knowledge on EoE. The objective of the organization is to establish and maintain a network and a communication platform for physicians and researchers with a specific interest in eosinophilic esophagitis (EoE) and eosinophilic gastro-enteritis and/or eosinophilic colitis in Europe.

STEERING COMMITTEE

The EUREOS steering committee 2021-2022 consists of

- Alfredo Lucendo (President 2021-2025)
- Arjan Bredenoord (Past-President)
- Luc Biedermann (Treasurer)
- Stephan Miehke
- Matteo Ghisa (Communication Officer)
- Christoph Schlag (Education Officer)
- Salvatore Oliva (Pediatric Officer)
- Helen Larsson (Content Manager)
- Ulrike von Armin (Guideline Officer)

MEMBERS

EUREOS is currently supported by 176 members from 16 different European countries.

We invite all physicians and scientist interested in EoE or wanting to support our work to become a member.

Members can participate in the annual general assembly and play an active role in deciding about future activities of EUREOS. Membership is free for physicians and scientists.

Furthermore, our members have access to the password-protected member area containing several valuable information and a slide library.

COMMUNICATION PLATFORM

Website

In 2019/20, EUREOS has harmonised the patient-oriented information platform EoE LINK with the EUREOS communication platform for health professionals and researchers at www.eureos.online. The new EUREOS website consists of two sections: patient-specific information in the «Patients» section, information for health professionals and researchers on the disease in general, and diagnostic and therapeutic algorithms in the «Professionals» section.

EUREOS supported the activities of the European EoE day (May 2022) through its presence in various events throughout different cities:

- Dr. Alfredo J Lucendo participated in the III Congress of Patients, held in Madrid on May 21, 2022, as well as in the main act of the event for Spain on May 22.
- EUREOS has launched a free online training course on EoE open to various specialists, with the collaboration of several international experts on the disease.

PAST & CURRENT ACTIVITIES

RESEARCH

EoE CONNECT

European Registry of Clinical, Environmental and Genetic Determinants in Eosinophilic Esophagitis

In 2016 EUREOS created an advanced multilingual EoE database with the aim to improve knowledge on epidemiology, its evolving trends, and on its burden to the health systems across Europe. The registry serves as a base for implementation of further prospective collaborative studies and is open to patients from all Europe. To date 1882 patients have been registered in EoE CONNECT. Detailed research objectives are the following:

- To describe the socio-demographical and clinical characteristics as well as personal antecedents of EoE patients.
- To examine the relationship between time of disease onset, length of diagnostic delay, and disease phenotypes.
- To determine the influence of environmental and genetic factors on the time of onset, natural history and course of EoE.
- To analyse the use, effectiveness, and safety of the different therapeutic interventions in EoE, both in short and long term, using the standardized set of outcomes.
- To examine the burden of disease costs associated with EoE in adults.

EoE CONNECT is run under the patronage of EUREOS with a scientific committee of ten international EoE experts. Contributors, that have added more than 30 patients in the EoE registry, can submit a study request to the scientific committee using the data in the EoE registry. The following studies have been published using the EoE CONNECT database:

- Accurate and timely diagnosis of Eosinophilic Esophagitis improves over time in Europe. An analysis of the EoE CONNECT Registry. (*United European Gastroenterol J.* 2022 Jun;10(5):507-517)
- EoE CONNECT, the European Registry of Clinical, Environmental, and Genetic Determinants in Eosinophilic Esophagitis: rationale, design, and study protocol of a large-scale epidemiological study in Europe (*Therap Adv Gastroenterol.* 2022 Feb 2;15:17562848221074204.)
- Efficacy of proton pump inhibitor therapy for eosinophilic oesophagitis in 630 patients: results from the EoE connect registry (*Pharmacol Ther.* 2020 Sep;52(5):798-807. doi: 10.1111/apt.15957. Epub 2020 Jul 17.)

- Efficacy of Therapy for Eosinophilic Esophagitis in Real-World Practice (Clin Gastroenterol Hepatol. 2020 Jan 25;S1542-3565(20)30103-8)

Industry-driven clinical trials

EUREOS has been approached by several pharmaceutical companies to collaborate in their clinical trials. If you are interested in participation as a study centre and you have the facilities, please contact us.

EDUCATION

INTERNATIONAL EVENTS

Due to the Corona pandemic, EUREOS held in 2021 its forth EoE Symposium as a virtual event during UEGW.

Main topics were:

- EUREOS EoE registry: Real-world data on EoE (Alfredo Lucendo, Spain)
- EUREOS EoE patient follow up project: Why? What? When? (Ulrike von Armin, Germany)
- Novel therapeutic options on the EoE horizon (Stephan Miehlke, Germany)

EUREOS-TIGERS JOINT WEBINAR

As a transatlantic educational collaboration Arjan Bredenoord initiated this educational EoE curriculum in November 2020. This successful format continued in 2021-22 with a total of six editions. In total, about 1000 EoE specialists participated in the training to deepen their knowledge in the field of EoE.

EOE ONLINE COURSE

As a contribution to the first European EoE Day that took place on 22 May 2022, EUREOS has launched an EoE Teaching Platform for healthcare professionals. This online course explains current knowledge about the epidemiology and etiology of EoE, methods for its diagnosis, and therapeutic alternatives. In addition, it presents the lines of research in progress on future therapies and highlights the areas of research that are still pending. To access the online course please visit eureos.online.

EXPERT RECOMMENDATIONS

EoE CORE OUTCOME SET PROJECT (COREOS)

Core outcome sets are an agreed, standardised list of outcomes that should be measured

and reported in all trials in specific clinical areas. We aim to develop a core outcome set for EoE, thus coming up with recommendations for endpoints in clinical trials and other EoE studies.

Under the patronage of EUREOS, the COREOS project was launched in 2018 in collaboration with CEGIR, EGID Committee of AAAAI, and Alimentiv (former Robarts Clinical trials).

In 2021, the COREOS final report was published.

- A Summary of the Meetings of the Development of a Core Outcome Set for Therapeutic Studies in Eosinophilic Esophagitis (COREOS) International Multidisciplinary Consensus (Gastroenterology. 2021 Sep;161(3):778-784)
- Therapeutic Studies in Eosinophilic Esophagitis (COREOS) International Multidisciplinary Consensus (Gastroenterology. 2021 Sep;161(3):778-784.)
- Development of a Core Outcome Set for Therapeutic Studies in Eosinophilic Esophagitis (COREOS): An International Multidisciplinary Consensus (Gastroenterology. 2021 Sep;161(3):748-755.)
- Development of a core outcome set for therapeutic studies in eosinophilic esophagitis (COREOS) (J Allergy Clin Immunol. 2021 Jul 6;S0091-6749(21)01059-9.)

EUREOS EOE PATIENT FOLLOW UP PROJECT: WHY? WHAT? WHEN?

Uncontrolled inflammation in EoE may lead to complications such as strictures. In daily practice, gastroenterologists face the challenge that symptoms and PROs do not always match histological findings; uncontrolled inflammation and fibrosis are the result.

To close this gap, a structured patient follow-up is necessary. Under the patronage of EUREOS, the Patient Follow-up Programme was therefore launched by Ulrike von Armin, with the aim of developing follow-up expert recommendations on „why“, „how“ and „when“ to follow-up EoE patients. The publication of these recommendations is expected end of 2022.

RENEWAL OF EUROPEAN GUIDELINES ON EoE

The current European Guidelines on diagnosis and management of EoE date back to 2017. The diagnostic and therapeutic armamentarium have developed since; thus the guidelines need to be renewed. Under the patronage of EUROES this process has been initiated by Alfredo Lucendo. Publication of the renewed Guidelines is expected for 2023.

ACKNOWLEDGEMENTS

We thank our corporate members for their financial support.

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