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Launch of the ACARE Chronic Angioedema Registry (CARE)

Thomas Buttgereit*1, Pavel Kolkhir2, Annika Gutsche2, Felix Aulenbacher2, Karsten Weller2, Markus Magerl2, Henriette Farkas3, Anete Grumach4, Marcus Maurer2

1Charité – Universitätsmedizin Berlin, Institute of Allergology IFA, Dermatology, Berlin, Germany, 2Charité – Universitätsmedizin Berlin Institute of Allergology IFA, Dermatology, Berlin, Germany, 3Hungarian Angioedema Center of Reference and Excellence, Department of Internal Medicine and Haematology, Semmelweis University, Budapest, Hungary, 4Clinical Immunology, University Center Faculdade de Medicina do ABC, Santo Andre, Brazil

Introduction & Objectives:

Angioedema is a paroxysmal, localized and self-limiting swelling of the subcutaneous and/or submucosal tissue, due to a temporary increase in vascular permeability. Angioedema can be heterogeneous, can occur only once or be chronic (recurrent), with or without wheals, hereditary or acquired, due to mast cell mediators or bradykinin or unknown mechanisms. Despite the high frequency of chronic angioedema and the availability of some retrospectively assessed data on the epidemiology, comorbidities, duration of disease, course of disease, underlying causes, treatment response and medical expenses, many types of angioedema are still insufficiently investigated. A disease registry is an appropriate tool to assess these features in a real-life setting. For this reason, the Chronic Angioedema REgistry (CARE) was initiated in 2023 by the global network of Angioedema Centers of Excellence and Reference (ACARE) as the first medical registry for recurrent angioedema.

The objective of this global registry is to improve the knowledge of angioedema by collecting and analyzing data of patients with different forms of recurrent angioedema in the areas mentioned above and, therefore, to improve the understanding of the disease and its types and subtypes.

Materials & Methods:

CARE is a web-based international investigator-initiated, open-ended registry, driven by the academic and scientific interests of its participants. CARE is observational (non-interventional) and collects real life data on all types of chronic angioedema, i.e. mast cell-mediated angioedema with and without wheals, bradykinin-mediated angioedema, hereditary angioedema, drug-induced angioedema, and angioedema of unknown origin. Any physician treating patients with angioedema, regardless of location, medical specialty, or type of practice setting is invited to participate in CARE. CARE aims to collect data on all patients with different types of angioedema, with no intentional selection or exclusion criteria.

Core variables of this registry, assessed at baseline and every 6 months, include: Demographic data, duration of disease, course of the disease, frequency of angioedema, underlying causes, comorbidities, triggering factors, treatment response, disease activity, disease control, quality of life impairment, direct health care costs, and absence from work/school. Furthermore, angioedema related biomarker samples shall be collected in selected ACAREs. CARE core variable data are analyzed twice yearly, and specific analyses are done for investigator-proposed research questions.

It is planned to enroll at least 1000 patients in the first 3 years in CARE to generate a data basis that is comprehensive enough for several types of sub analyses.