Registry activities and progress report 2014-2016:

Initiation of a novel European calciphylaxis network EuCalNet

The goal of the European calciphylaxis registry and all international partners involved is to establish a network for clinical and scientific exchange in the field of calciphylaxis. The European Calciphylaxis Network (EuCalNet) now includes seven European countries: Belgium, Portugal, The Netherlands, Spain, Italy, France, and Germany.

EuCalNet will allow users in different countries, sites and different languages to enter patient data and participate in the registry activities. Data storage, quality control and analyses will take place within the study center in Aachen (Figure 1). We kindly invite physicians to visit our country-specific websites which will give a comprehensive overview of our activities in the field of calciphylaxis.

Please visit: https://www.calciphylaxis.net/eu

Endorsement by ERA-EDTA: The EuCalNet project is an integral part of the work package of the ERA-EDTA scientific working group “CKD-MBD” and this close collaboration has led to a strong overlap between EuCalNet consortium partners and working group board members.

Please visit: www.era-edtaworkinggroups.org/en-US/group/ckd-mbd

EuCalNet maintenance and funding:

As with the German registry EuCalNet is currently supported by grants from Amgen and Sanofi.

The support of EuCalNet by funding sources is being acknowledged, previously and in the future as well, in any resulting scientific publication, study reports, all oral and other presentations, or abstract submission to a scientific or medical congress about EuCalNet. Any trademarks or other distinctive signs belonging to companies supporting the initiation and maintenance of EuCalNet can be used by mutual agreement in any statements or public announcements. Furthermore, EuCalNet offers various choices for funding sources to expand their internet presence via the registry website (links, logos, or any other information).

Historic background: Previous registry work in Germany

2006-2015: Long-term nationwide registry

For further details of the German registry data analysis please refer to the following publication:

Overview of EuCalNet implementation and structure

Since 2014: EuCalNet

The internet-based multilingual registry EuCalNet was initiated in 2014 which took over the basic structure applied in the former German registry. However, based on ongoing data management and quality checks significant changes were implemented. All entered data is stored fully encrypted in a separate database equipped with an audit trail covering all changes. The central ISO/IEC 27001 norm - certified computing center complies with the highest security standards in all areas like hardware, protection of data privacy and staff qualification.

EuCalNet Milestones:

A crucial milestone en route to a comprehensive transnational registry initiative was reached in December 2015: the “first-patient-in” (Germany). Currently, records from further German patients with confirmed CUA have been entered into the database since the beginning of 2016. In the meantime, the registry has been approved in Italy where Prof. Sandro Mazzaferro, Rome, and his team have already recorded data from first two CUA patients in August and are now proceeding with further cases. The other EuCalNet countries will follow step-by-step depending on country-specific ethical conditions and provisions concerning the data safety restrictions and authorization of the registry.

Awareness level of EuCalNet:

Increasing awareness of the registry →
Increasing awareness and knowledge of the disease →
Improving patient care!

Marketing activities were undertaken by the international study team to increase awareness of the registry and to boost the motivation for participation. Various symposia, workshops and recent publications on new insights on CUA will help

- face the challenge of unmet medical needs in calciphylaxis and
- facilitate exchange of expertise and networking between scientists and clinicians.

Scientific symposia on CUA based on the multinational EuCalNet registry work (2014/2015/2016) have been organized annually since 2014 (please see Appendix for detailed information)

Previous and recent publication activities on CUA 2014 – 2016 guarantee visibility for the study team as well as for industrial partners within the scientific community. These publications and the ongoing EuCalNet activities pursue the following goals:

- distribute knowledge and expertise about calciphylaxis to a broad audience
- share therapeutic experiences and transfer expert knowledge to treating physicians
- increase the awareness of the disease and create the basis for prospective interventional trials

List of recent publications:


Brandenburg VM, Martin H, Sohn CM, et al.: Calciphylaxie. DMW 2015


Future activities:

For 2017, the EuCalNet Team is preparing:

- additional peer-reviewed publications
- abstract submissions to nephrology and rare diseases congresses
- presentations for medical and CME symposia
- newsletter and additional paperework to inform and to sensitize a broader public and physicians regarding CUA beyond the scientific community

Supervision of the overall progress is conducted by Prof. Vincent Brandenburg, nephrologist, associate professor and senior consultant at the Department of Cardiology, Intensive Care Medicine and Vascular Medicine, University Hospital of the RWTH Aachen, Germany, responsible for all scientific and managing activities of the consortium. He is supported by Joanna Korbiel, clinical trial manager at the Center for Translational & Clinical Research Aachen (CTC-A), UK Aachen. The Aachen Team acts as Coordinating Center, and facilitates coordination and management of all registry activities of all participants to promote an efficient and effective management for this complex project.