THE GREEK REGISTRY OF CEREBRAL ANEURYSMS
(GRECA)

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Background
The worldwide prevalence of cerebral aneurysms is approximately 3% with an overall female-to-male ratio close to 1.6:1. However, exact regional patterns of the disease, reflecting different risk factor profiles, remain unknown. Detailed nationwide reports are produced regularly only in a few countries (e.g. Finland and Japan) with all other similar datasets being essentially estimates. Recognising the problem, the Greek Neurosurgical Society announces the official launch of the Greek National Registry of Cerebral Aneurysms (GRECA).

Methods
The Greek National Registry of Cerebral Aneurysms is a project that our team has been working on for the past couple of years. It involves an online, prospective and continuous database that will be operated on behalf of the Greek Neurosurgical Society and will collect national level data on both ruptured and unruptured cerebral aneurysms. The registry has been operational since the 1st of January of 2020 and its software has been developed by RISA Ltd in accordance to GDPR provisions. Access to the registry is password protected and will be granted to all Greek Neurosurgical Departments. Data collected include details on: (1) epidemiology, (2) associated co-morbidities, (3) mode of presentation, (4) treatment, (5) complications, (6) outcome and (7) follow up. The dataset scheme is based on NIH Common Data Elements (CDEs). Appropriate coding (CDE ID) has been used. Each department is required to appoint a designated operator - preferably a senior member of stuff - who will be supervising data collection and submission. Structured training of operators through online short courses (including the Good Clinical Practices course), continuous feedback and a 24/7 running Helpdesk will assure data quality and consecutiveness. Monitoring of the whole process will be based on random case controls conducted by the scientific coordinator’s team as well as comparison of numbers going in the registry with those expected by what we already know on the epidemiology of the disease. Of note, data access will be granted to appropriately designed and approved research projects with the permission of the Board of the Greek Neurosurgical Society.

Results
Due to the COVID associated disruptance of everyday activities within the Greek National Health System, recruitment has been - for the first half 2020 - slow with only 23 aneurysm cases on the records so far. However, we remain optimistic and we believe that data input will pick up. Statistical analysis of such numbers cannot provide solid results and thus will not be presented here.

Conclusion
The primary purpose of our registry is to serve as a tool for disease monitoring. Providing data on epidemiology, presentation and treatment of aneurysms (but also SAH) throughout the country, it will help us evaluate our everyday practice and shape future public health policies. Apart from its value in health policy-making, GRECA will also offer insights on the disease itself. Future prospects include expansion of the database to other vascular pathologies such as Stroke and AVMs as well as collaboration with any similar projects in other countries (e.g. the Swiss SOS initiative).