Joint Annual Meeting SGK/SGHC/SGP - Abstract Submission

Topic: 6. Cardiac imaging, congenital and pediatric cardiology

SGK16-1045

Swiss adult congenital heart disease registry (sacher) - rationale, design and first results

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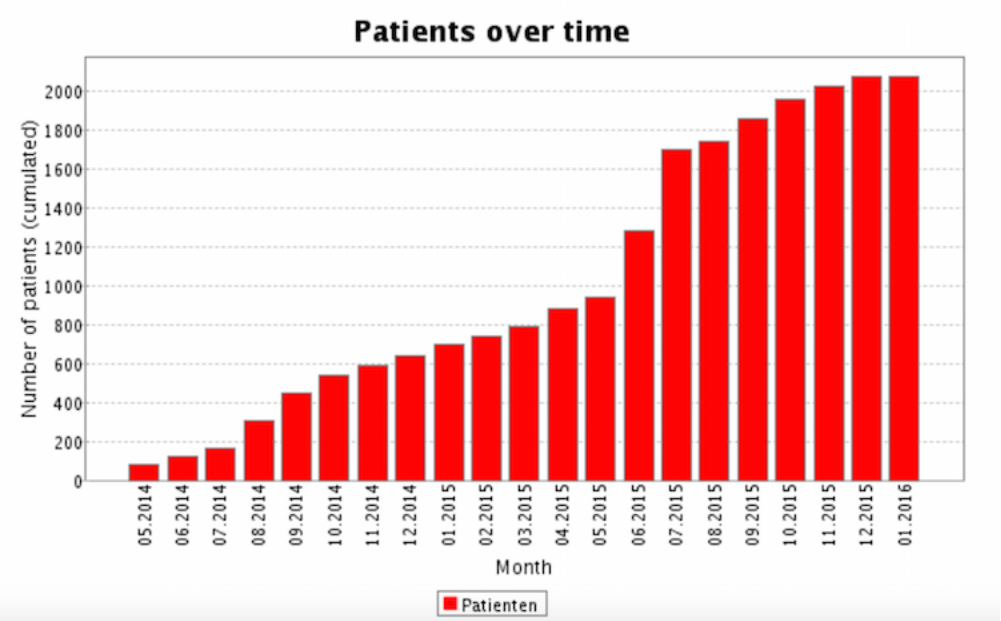
Which of the below societies are you most strongly affiliated with?: SGK

Introduction: In 2013, an initiative was started to develop a national registry of adults with congenital heart disease in Switzerland (SACHER). The aim of the registry is to create a prospective data collection as the basis of future national studies to improve the long-term outcomes of these patients. The first results are reported in this abstract.

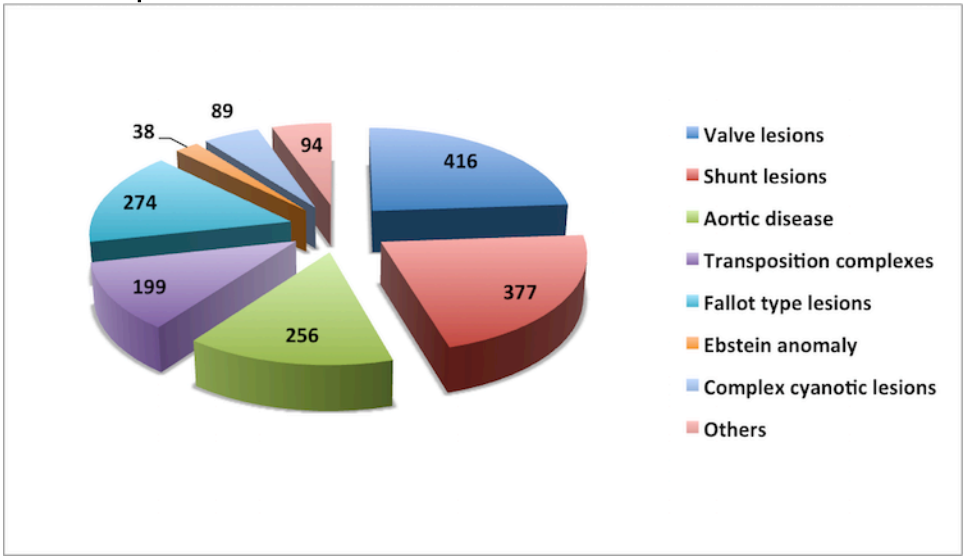
Methods: All patients with structural congenital heart defects or Marfan syndrome are eligible to participate. Patients were recruited from specialized adult congenital heart disease clinics (University Hospital of Basel, Berne, Lausanne and Zurich; Kantonsspital St. Gallen). The ethics review boards of all participating medical centers have approved the SACHER registry. Patients are asked to participate by their cardiologist. After informed consent, each patient will be anonymized and the data will be entered in an online register (secuTrial®). The system of secuTrial® provides an Internet-based support for query management, monitoring, reporting and coding. The product has been developed in accordance with all regulatory standards. Baseline data of interest include date of birth, gender, main diagnosis, type of cardiac repair and late complications amongst other.

Results: From May 2014 to December 2015 more than 2000 patients have been included into the registry; of those, 1743 (84%) have complete baseline data. 54% are male. Mean age of the patients with complete data is 32 years; more than 83% are younger than 40 years. 57% (n=987 patients) have lesions of moderate or great complexity. Isolated aortic valve disease (congenital aortic stenosis and bicuspid aortic valve) is the most prevalent main diagnosis (n=277, 16%), followed by tetralogy of Fallot (n=208, 12%), aortic coarctation (n=188, 11%), D-transposition of the great arteries (n=169, 10%) and ventricular septal defects (n=159, 9%). 72% of patients (n=1257) had prior cardiac surgery, of those 51% (n=638) needed subsequent cardiac surgery or intervention after their main repair. In 8% of patients devices have been implanted (109 pacemaker and 35 ICD/CRT). Supraventricular tachycardia and atrial fibrillation are the most prevalent late complications (n=195, 11% and n=144, 8% resp.) followed by pulmonary hypertension (n=109, 6%), stroke (n=99, 6%) and endocarditis (n=86, 5%).

Picture/Graph:



Picture/Graph 2:



Conclusion: The SACHER registry facilitates research on prevalence and long-term outcome of adults with congenital heart disease.

The presenting author fulfills the above conditions and wants to apply for a travel award: No, please do not consider my abstract for prize evaluation.

Disclosure of Interest: None Declared