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Patient Registry of the Competence Network for Congenital Heart Defects in Germany

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Introduction: Many CHD patients remain chronically ill throughout their lives and require lifelong care. Since patient numbers are small and due to the high variability of disease patterns, there is a lack of sufficient data for the development of adequate treatment and care. Therefore in 2003 the German cardiac associations have initiated a patient registry that collects data and (since 2008) biomaterial samples from patients of all ages and from all over Germany on a long-term basis in a central database & biobank facility.
Methods: Patients (or parents of underage patients) enrol on their own account via a registration form that is distributed by most German heart centres and parents' associations. On registration and entry of personal data (IDAT-database), a unique patient identifier (PID) is generated. The PID applies for all databases within the Competence Network (including a clinical study- and image database) and ensures a correct assignment of data sets. Health-related and medical data are based on patient questionnaires and physician's medical reports and are stored in a separate database (MDAT-database) to ensure data privacy. Diagnoses and procedures are classified using the EPC-Code/Short List. EDTA-blood samples are collected via (i) direct contact to registry patients and their families, and (ii) cooperation with several involved clinical centres in Germany. DNA isolated from EDTA-blood is stored in a central facility.
Results: Presently (January 2011) the registry comprises a total of 40,013 patients. The large majority (84%) of participants are underage, sex is evenly distributed. Simple heart lesions (VSD, ASD, PDA) represent 51%, moderate (TOF, ISTA, AoV, TGA, AVSD, PaV, DORV, PAPVC, TAPVC, HRST) 42%, and severe/complex (DIV, CMP, PA, CCT, TAC, HLHS, Marfan) 7%. Based on registry data and directed recruitment of participants numerous studies have been initiated regarding quality of life, social situation, patient communication, genetic causes, as well as clinical studies. The DNA collection presently comprises 712 samples covering a wide range of CHD phenotypes. The sample collection will be extended to include also cardiac tissue, a pilot phase has started in autumn 2010.
Conclusions: The patient registry and biobank facilitates collaborative and translational research on congenital heart defects.