

Cardiological Subspecialty Care in Europe

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From 2000 to 2005, the average total prevalence of congenital heart disease (CHD) was 8.0 per 1000 births and live birth prevalence was 7.2% per 1000 births (EUROCAT Central Registry, data from 29 population-based congenital anomaly registries in 16 European countries covering 3.3 million births). The total prevalence of non-chromosomal CHD was 7.0 per 1000 births, with severe CHD in 2.0 per 1000 births, of which 8.1% were perinatal deaths and 40% were prenatally diagnosed (Dolk H, 2011).

Thus, about 36.000 live-born children are diagnosed with CHD throughout the EU each year. More than 30% of them will require treatment- either corrective/ palliative surgery or catheter intervention (valvuloplasty, device closure etc.) or both (hybrid therapy). 50% of those procedures will have to be performed within the first year of life.

High-end treatment of CHD requires care in a tertiary cardiac centre. In CHD surgery, a frequency of 600-700 procedures / year / 10 million inhabitants can be expected. Its quality can be monitored by the ARISTOTLE complexity score which was developed by the EACTS (European Association of Cardiothoracic Surgery) (Lacour-Gayet F, 2000). High quality care in CHD is often life-long and has to address a multitude of medical and psychosocial issues.

The AEPC (Association for European Congenital Cardiology; www.aepc.org) lists cardiac centres in 19 / 38 countries, only a small number of them in South-Eastern Europe. Data about procedures are missing, from personal communication within the European paediatric cardiology community, fact-finding missions and humanitarian projects it is evident that there is still a significant number of children in whom CHD takes its natural course. Such diversity of care is also well known within ECHDO (European Congenital Heart Disease Organisation) - the umbrella organisation of European self-help groups (www.echdo.org).

Within the last two decades, progress in paediatric cardiology and cardiac surgery made survival to adulthood possible. This is true for Western and Central Europe. The total number of European CHD- patients is now approaching 4.2 million, 2.3 of them being adults (Marelli AJ, 2007). However, data from the GUCH (Grown-Up CHD) Working Group of the ESC (European Society of Cardiology) indicate that only 7.1% of them are currently receiving adequate care (Moons P, 2010).

Thus, diversity of care in CHD does not only affect children with CHD, but also adults with CHD who survived childhood.