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Introduction

ECHSA congenital database

The European Congenital Heart Surgeons Foundation (Association since 2003), established in 1992, created the European Congenital Heart Defects Database (ECHDD), precursor of today's ECHSA Congenital Database.

The ECHDD was supervised by Martin Elliott and based at the Great Ormond Street Hospital for Sick Children, London, UK.

In 1998 the ECHDD was moved to, for legal and logistical reasons, the Department of Cardio-Thoracic Surgery, Children's Memorial Health Institute, Warsaw, Poland under the responsibility of Dr. Bohdan Maruszewski.

Simultaneously since 1994, substantial amount of work was done within the European Association for Cardio-Thoracic Surgery (EACTS) on establishing the EACTS Database named European Cardiothoracic Surgical Registry.

In September 1999 during the EACTS Annual Meeting in Glasgow, the final decision was made that ECHDD would become a part of the EACTS Database Project. At the same meeting an International Nomenclature for Congenital Heart Surgery was officially adopted; this was the outcome of one year's work of the International Nomenclature and Database Committees for Congenital Heart Disease of both EACTS and the American Society of Thoracic Surgeons (STS).

Over the course of eight meetings at several venues on both sides of the Atlantic, in 1998 and 1999, an International Nomenclature and Database Committee met with 36 experts from the membership of the EACTS, STS, AATS, AHA associated surgeons and cardiologists from the United States, Canada, Australia and Europe.

This resulted in the International Nomenclature for Congenital Heart Surgery including the Minimum Data Set of 21 items and the lists of 150 Diagnoses, 200 Procedures, 32 Complications, as well as 28 extra cardiac anomalies and 17 preoperative risk factors.

This International Language for CHD fulfills the following expectations and requirements:

- simple, limited and exclusive
- complete
- usable by surgeons and cardiologists
- includes congenital heart surgery, lung surgery, ECMO and arrhythmia procedures.
- respects published classifications
- provides synonyms for similar items

The comprehensive data set that includes all predicted variables is detailed enough to generate risk stratification analysis. The Minimum Data Set includes the "short lists" that would create an essential data set mandatory for transfer and analysis of the information, and it is necessary for evaluation and the comparison of outcomes and trends.

General rules of the ECHSA congenital database

Access to the Database - software, continued support and reports is available via Internet for all cardiothoracic units in Europe and worldwide.

No personal data contained in the ECHSA Congenital Database is accessible by an individual or institution. Only surgeons and centers know their own identities and those of their patients. Patient's personal data are not transmitted at all and patient identification can be replaced with another number, before transmission to the Database.

Participation in the ECHSA Congenital Database (www.echsacongenitaldb.org) is a major benefit of ECHSA Membership. An important aim of the founding members of ECHSA was to collect data on the outcomes of Congenital Heart Surgery procedures across Europe, thereby making possible comparison of results and identification of risk factors, as well as targeting research activities. This required good quality data obtained on a large scale from numerous European congenital surgical cardiothoracic units, as well as data validation and verification. Such data collection allows risk stratification and helps define optimal surgical treatment for certain subsets of patients. It is hoped that this effort will contribute to improved early and late survival as well as the quality of life of surgically treated patients with Congenital Heart Disease across Europe.

The European Congenital Heart Surgeons Foundation, which was established in 1992 (and re-organized as the European Congenital Heart Surgeons Association in 2003), created the European Congenital Heart Defects Database (ECHDD),

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precursor of today's ECHSA Congenital Database (ECDB).

Today, the immediate aim of the ECDB is to collect data relating to treatment of patients with congenital heart disease, including diagnoses, risk factors, surgical and other procedures, as well as early and, eventually, long – term outcome.

There are currently 387 registered centers from 82 countries. The ECDB is accessed on an Institutional Level, with an annual fee needed for access.

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