

## *From the Editor-in-Chief*

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PROVIDING A STANDARDISED SYSTEM FOR describing the malformations found in neonates, infants, children and adults with congenital disease has been a much-sought goal for many working in this field over the last half-century. We are now close to achieving that goal. At the recent World Congress of Pediatric Cardiology and Cardiac Surgery, the International group formed to address this problem presented its suggested solution. In light of the importance of these activities, I asked some of the

major contributors to these happenings to summarise the current situation. Rodney Franklin, Marie Béland, and Otto Krogmann agreed to undertake this task. The report below is their summary of the activities of their colleagues.

*Robert H. Anderson*  
*Editor-in-Chief*  
*Cardiology in the Young*

## Mapping and Coding of Nomenclatures for Paediatric and Congenital Heart Disease

On behalf of the International Society for Nomenclature of Paediatric and Congenital Heart Disease, we are pleased to summarise the outcome of the session of 2 hours allocated to the International Society during the Fourth World Congress of Pediatric Cardiology and Cardiac Surgery, held in Buenos Aires, Argentina, on 19th September, 2005. The session was entitled “The Second International Nomenclature Summit for Paediatric and Congenital Heart Disease”, and was presented by the International Working Group for Mapping and Coding of Nomenclatures for Paediatric and Congenital Heart Disease, which works under the aegis of the International Society for Nomenclature of Paediatric and Congenital Heart Disease. Despite the inevitable clash of this meeting with several other simultaneous sessions at the Congress, our meeting was attended by approximately 125 people. There were 9 well received presentations from members of the Nomenclature Working Group (Table).

The main topics were:

- The goals achieved by the 12 members of the Nomenclature Working Group since its inception at the previous World Congress in Toronto in 2001;
- The foundation and goals of the not-for-profit International Society for Nomenclature of Paediatric and Congenital Heart Disease, established in January 2005.

Over the last four years, the Nomenclature Working Group has met seven times, over a total period of 33 days, so as to fulfil its remit of crossmapping the two published Long Lists from the year 2000: the 4,777

itemed, “atomic” based list derived from the European Paediatric Cardiac Code sponsored by the Association for European Paediatric Cardiology, and published as Supplement 1 of Volume 10 of *Cardiology in the Young*, and the 7,623 itemed, “molecular” based system sponsored by the Society of Thoracic Surgeons and the European Association of Cardio Thoracic Surgeons, published as a supplement to Number 4, Volume 69, of the *Annals of Thoracic Surgery*. The result has been the creation of the International Paediatric and Congenital Cardiac Code, with a numerical core of 7,623 items and two versions:

- That derived from the European Paediatric Cardiac Code;
- That derived from the International Congenital Heart Surgery Nomenclature and Database Project.

Despite their very different structures, these two versions now map fully to each other via numerical codes developed using a template of the 6-digit codes of the European Paediatric Cardiac Code. In addition to the two published Long Lists, the International Paediatric and Congenital Cardiac Code contains elements from the Boston-based Fyler codes, and the Canadian nomenclature system. Full mapping of these lists to the International Code is also in progress. Furthermore, the International Code is crossmapped to the 9th and 10th revisions of the International Classification of Diseases provided by the World Health Organisation, thus facilitating the central return of data as mandated by many governments. Although nearly all congenital and paediatric cardiac lesions have been examined and crossmapped by the Nomenclature

Table. The programme for the 2 hour session held in Argentina on September 19, 2005.

Welcome	<i>Martin J. Elliott, London, United Kingdom (President of the International Society)</i>
Overview of Project	<i>Christo I. Tchervenkov, Montreal, Canada (Vice-President and Secretary)</i>
Why this Project Exists	<i>Jeffrey P. Jacobs, St. Petersburg, United States of America</i>
Nomenclature & electronic medical record	<i>Rodney C. G. Franklin, London, United Kingdom</i>
Cross-Map and Super-Tree	<i>Marie J. Béland, Montreal, Canada (Treasurer)</i>
The Pathologist's Point of View	<i>Paul M. Weinberg, Philadelphia, United States of America</i>
Industry Standard and Applications	<i>Steven D. Colan, Boston, United States of America</i>
Database Applications	<i>Bohdan Maruszewski, Warsaw, Poland</i>
Concluding remarks & panel discussion	<i>Jeffrey P. Jacobs &amp; Panel</i>

Working Group, with new numerical codes and nomenclature created as required, there remain a few key areas to cover. These include arrhythmias, transcatheter interventional procedures, fetal cardiology, coronary arterial anomalies, and pre-procedural risk factors with post-procedural complications. Meetings are already arranged to cover these topics over the next two years, in liaison with invited experts from the specific fields and other interested Societies.

The resultant International Paediatric and Congenital Cardiac Code will provide the ability to code for a near-exhaustive list of phenotypes and procedures, by crossmapping any existing nomenclature list to it, whatever the language or related discipline. The Short Lists of the European Paediatric Cardiac Code and the International Congenital Heart Surgery Nomenclature and Database Project, which are used primarily for multi-institutional and international audit of databases, and which are derived directly from their respective Long Lists, enable the huge number of over 50,000 patients registered in each database to be used together. This has already begun to bear fruit, with work in hand analysing the potential usefulness of risk stratification using the Aristotle system. The structure and content of the Short Lists remain the purview of the Societies and organizations who created them. Future work of the International Society and its Nomenclature Working Group also includes close cooperation with the Clinical Terms project of Systematized Nomenclature of Medicine International, SNOMED CT<sup>®</sup>; a division of the American College of Pathologists, supported by multinational governments, this being an initiative for nomenclature and coding to be incorporated into the Electronic Medical Record.

The first versions of the International Paediatric and Congenital Cardiac Code were published on the world wide web in February 2006, after a process of item-by-item validation of the terms crossmapped to date. A downloadable free version of the regularly updated International Paediatric and Congenital Cardiac Code is available on the International Society web site ([www.ipccc.net](http://www.ipccc.net)) using copyright registration.

After the Nomenclature Summit, there followed a short business meeting of the International Society for Nomenclature of Paediatric and Congenital Heart Disease. As stated in its Constitution, the Society was established in 2005 "to standardize and maintain an international nomenclature system to enhance global communication and facilitate patient care, teaching and research into paediatric and congenital heart disease across disciplines". The Society includes representatives from Europe, North and South America, and Japan, and is interested in expanding to include interested individuals from across the globe, particularly if they wish to become members in the name of a group or Association with related interests. Future annual business meetings will occur the same week as the now annual meetings of the Nomenclature Working Group, which are scheduled for Venice, in June, 2006, and in Japan, in July, 2007.

To date, partial funding to support the meetings of the Nomenclature Working Group has originated almost exclusively from Canadian sources, including the Canadian Institutes of Health Research, the Heart and Stroke Foundation of Canada, the Montreal Children's Hospital Foundation and the Andy Collins for Kids Foundation of Canada. Further funding will need to be secured for the International Society and its Nomenclature Working Group to maintain and develop further the International Paediatric and Congenital Cardiac Code.

Any comments or questions regarding the International Society, the Nomenclature Working Group or the International Paediatric and Congenital Cardiac Code are most welcome. Communication with the International Society can easily be achieved via its website ([www.ipccc.net](http://www.ipccc.net)).

*Rodney C. G. Franklin, Marie J. Béland  
Otto N. Krogmann  
On behalf of the International Society  
for Nomenclature of Paediatric and  
Congenital Heart Disease*