

# Cardiology in the Young

## Special Supplement of Cardiology in the Young: Proceedings of the 2015 International Paediatric Heart Failure Summit of Johns Hopkins All Children's Heart Institute

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Florida, United States of America  
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SPECIAL SUPPLEMENT OF CARDIOLOGY IN THE YOUNG:

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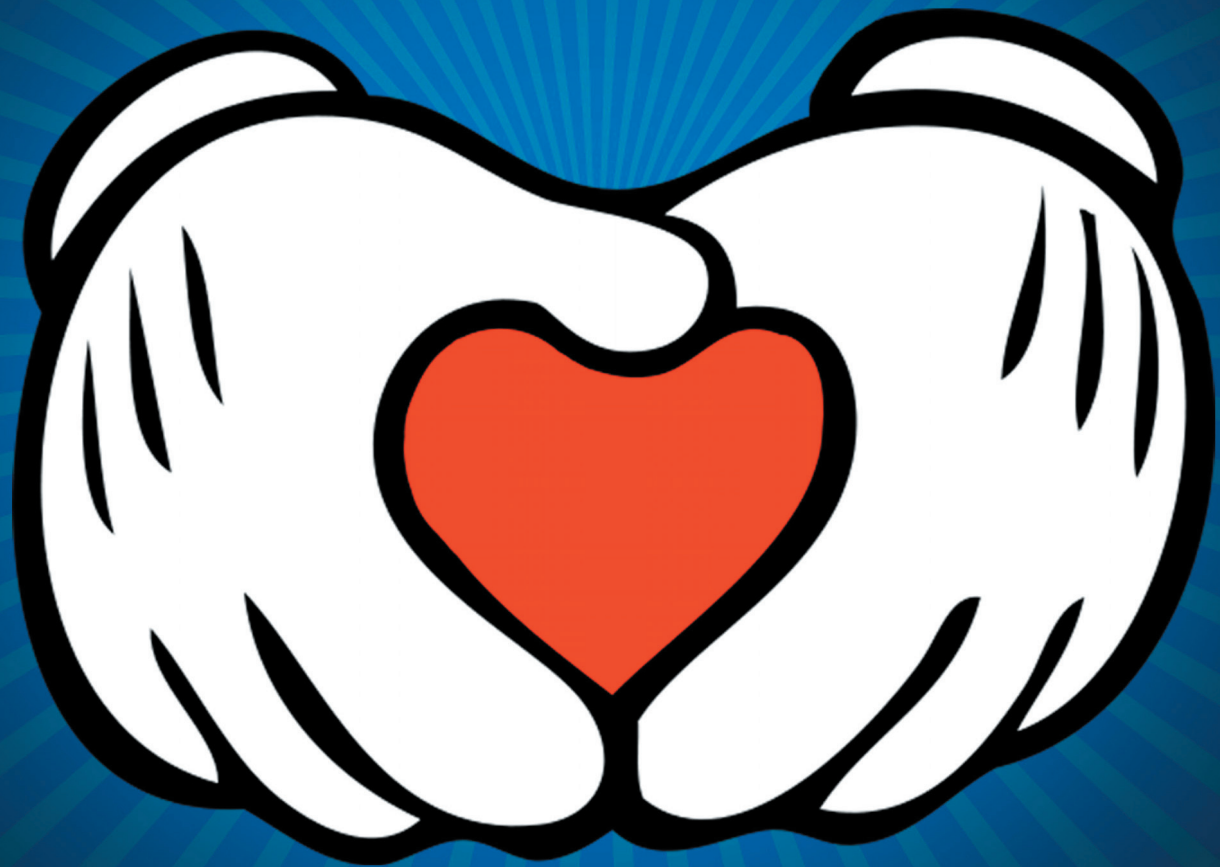
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## The International Society for Nomenclature of Paediatric and Congenital Heart Disease



THE INTERNATIONAL SOCIETY FOR NOMENCLATURE of Paediatric and Congenital Heart Disease (ISNPCHD) is an established not-for-profit organization, incorporated in Canada, with the collective mission to identify, standardize, and maintain an international system of nomenclature, the International Paediatric and Congenital Cardiac Code (IPCCC), to enhance global communication and facilitate patient care, research, and training in paediatric and congenital heart care across disciplines. In other words, the IPCCC provides a common language and terminology, inclusive of definitions and imaging, which covers the entire field of diagnostic and procedural terms for paediatric and congenital heart care. The IPCCC is the product of the cross-mapping work by the ISNPCHD Nomenclature Working Group during the decade following the publication in 2000 of two similar and complementary nomenclature systems, namely the International Congenital Heart Surgery Nomenclature and Database Project under the auspices of the European Association for Cardio-Thoracic Surgery and Society of Thoracic Surgeons, and the European Paediatric Cardiac Code under the auspices of the Association for European Paediatric Cardiology. The IPCCC is owned by the ISNPCHD but is digitally published for free download for private use ([www.ipccc.net](http://www.ipccc.net)) in these two Societal versions, both with a Long List of over 10,000 terms with qualifiers, and a Short List of up to 1000 terms for use in databases when comparing institutional outcomes, both nationally and internationally. The Long Lists of the IPCCC comprehensively cover the field of paediatric and congenital cardiac care, including diagnoses of congenital and related acquired pathology, comorbid conditions, transcatheter and operative procedures, and a full list of postprocedural complications. The Short Lists are used within databases across the world with over 500,000 registered patients. The ISNPCHD encourages the commercial use of the

IPCCC by requiring and providing free-of-charge license agreements for its use, to ensure that the IPCCC remains unaltered by parties other than the ISNPCHD.

Since 2007 the ISNPCHD has been operating through three working groups:

- The Nomenclature Working Group, which continues to maintain, develop, expand, update, and preserve the IPCCC;
- The Definitions Working Group, which is engaged in writing definitions for the terms in the IPCCC. More recently this initiative has focused on the terms provided by the ISNPCHD at the behest of the World Health Organization (WHO) for the 11<sup>th</sup> revision of the International Classification of Diseases;
- The Archiving Working Group, which is engaged in linking images and videos to the IPCCC, including cardiac morphologic specimens, echocardiography, angiography, computerized axial tomography, magnetic resonance imaging, intraoperative photographs and intraoperative videos.

The ISNPCHD, through the IPCCC, enables institutions from around the world to seamlessly communicate with each other, comparing and then improving outcomes and the quality of care that is given to children, young people, and adults born with malformed hearts. This common language enables institutions to learn from those hospitals performing best at a global level, as well as facilitating research projects, such as comparing the longer term quality of life and complications in those who have required operative and transcatheter interventions. In addition, the nomenclature with corresponding definitions and matching imaging, enhances teaching of this specialty to the next generation of clinicians dedicated to pediatric and congenital cardiac care, both in the developed and developing world.