

Cardiology in the Young

Sudden Cardiac Arrest in the Young: A Contemporary Perspective



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Association for European Paediatric and Congenital Cardiology (AEPC)



AEPC WAS FOUNDED IN LYON IN 1963 (as Association Européenne pour la Cardiologie Pédiatrique) and subsequently has created a network of specialists who are committed to the practice and advancement of Congenital Cardiology and closely related fields. *Cardiology in the Young* is the official journal of the AEPC. AEPC offers a free subscription of 'Cardiology in the Young' (CitY) as part of the annual membership fee. The membership also offers several other benefits.

The overall membership of the Association currently stands at 1300 paediatric cardiologists and other specialists working in the field of paediatric cardiology and its related disciplines. As far as we are aware, the AEPC is the largest democratically administered global association in the field of paediatric and congenital cardiology. Members of the AEPC originate from virtually all countries in Europe and it is encouraging that there are now increasing numbers of members from all the continents. New members are very welcome as they bring with them new ideas and innovations.

AEPC and its Working Groups aim to enhance collaboration amongst members for scientific research, promoting training, professional development and to maintain high standards of professional practice. The work on behalf of children and patients with congenital heart diseases is global and the AEPC has made itself a global organisation by its close collaboration with other international organizations. These include the European Society of Cardiology;

the Japanese Society of Paediatric Cardiology and Cardiac Surgery (JSPCCS); the European Association for Cardio-Thoracic Surgery (EACTS) and; the Adult Congenital and Pediatric Cardiology Section of the American College of Cardiology (ACC); the Asia Pacific Pediatric Cardiac Society (APPCS); the European Heart Surgeons Association (ECHSA), the World Congress of Paediatric Cardiology and Cardiac Surgery and several others.

Working groups

Several activities of AEPC are organized by the Working Groups. The Working Groups represent different subspecialties and specific areas of paediatric and congenital cardiology. The Association now has 13 Working Groups, to bring together workers with similar interests in order to facilitate research and collaboration and to organise teaching and training.

Annual meetings

An Annual Meeting and an Update-On Course are organised by the AEPC, usually in the third week of May in collaboration with one of the member countries. The AEPC organizes 2–3 Teaching courses for trainees in Paediatric Cardiology each year. Additional symposia and courses are usually a part of the annual meetings.

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) 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 11th 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.