



# Report From The International Society for Nomenclature of Paediatric and Congenital Heart Disease: Creation of a Visual Encyclopedia Illustrating the Terms and Definitions of the International Pediatric and Congenital Cardiac Code

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## Abstract

Tremendous progress has been made in the field of pediatric heart disease over the past 30 years. Although survival after heart surgery in children has improved dramatically, complications still occur, and optimization of outcomes for all patients remains a challenge. To improve outcomes, collaborative efforts are required and ultimately depend on the possibility of using a common language when discussing pediatric and congenital heart disease. Such a universal language has been developed and named the International Pediatric and Congenital Cardiac Code (IPCCC). To make the IPCCC more universally understood, efforts are under way to link the IPCCC to pictures and videos. The Archiving Working Group is an organization composed of leaders within the international pediatric cardiac medical community and part of the International Society for Nomenclature of Paediatric and Congenital Heart Disease ([www.ipccc.net](http://www.ipccc.net)). Its purpose is to illustrate, with representative images of all types and formats, the pertinent aspects of cardiac diseases that affect neonates, infants, children, and adults with congenital heart disease, using the codes and definitions associated with the IPCCC as the organizational backbone. The Archiving Working Group certifies and links images and videos to the appropriate term and definition in the IPCCC. These images and videos are then displayed in an electronic format on the Internet. The purpose of this publication is to report the recent progress made by the Archiving Working Group in establishing an Internet-based, image encyclopedia that is based on the standards of the IPCCC.

## Keywords

databases, cardiac nomenclature, congenital heart disease, Internet, cardiac encyclopedia, cardiac images, International Pediatric and Congenital Cardiac Code

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## Introduction

Over the past 2 decades, tremendous progress had been made in the field of congenital and pediatric heart surgery, and survival is now expected for many patients with heart disease that previously were considered untreatable. Further improvements in the quality of care provided to these patients with heart disease will be facilitated by the utilization and analysis of multi-institutional databases. To perform

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**Abbreviations and Acronyms**

AEPC	Association for European Paediatric Cardiology
AWG	Archiving Working Group
DWG	Definitions Working Group
EACTS	European Association for Cardio-Thoracic Surgery
ICD	International Statistical Classification of Diseases and Related Health Problems of the World Health Organization
IPCCC	International Pediatric and Congenital Cardiac Code
ISNPCHD	International Society for Nomenclature of Paediatric and Congenital Heart Disease
MRI	magnetic resonance imaging
NWG	Nomenclature Working Group
STS	Society of Thoracic Surgeons
UKCCAD	United Kingdom Central Cardiac Audit Database

meaningful multi-institutional analyses, any database must incorporate the following 6 essential elements<sup>1-144</sup>:

1. Use of a common language and nomenclature<sup>3-37, 43-46, 48-53, 57, 59, 63, 64, 70, 73-76, 80, 83-85, 90-96, 108-120, 126, 129, 135-144.</sup>
2. Use of a database with an established uniform core data set for collection of information<sup>1-5, 37, 40-42, 44-46, 53, 59, 62, 63, 69, 70, 74, 80, 84, 85, 88, 90-103, 123, 124, 128, 131-144.</sup>
3. Incorporation of a mechanism to evaluate case complexity<sup>38, 39, 43, 47, 54-56, 58-61, 63-66, 70-72, 77-82, 84, 86, 87, 90-92, 102, 104, 105, 121, 122, 124, 127, 129, 130, 135-144.</sup>
4. Availability of a mechanism to assure and verify the completeness and accuracy of the data collected<sup>59, 63, 67, 68, 70, 80, 84, 90-92, 106, 141-144.</sup>
5. Collaboration between medical and surgical subspecialties<sup>84, 90-92, 108-120, 142-144.</sup>
6. Standardization of protocols for lifelong longitudinal follow-up<sup>84, 89, 90-92, 107, 125, 126, 143, 144.</sup>

The foundation of multi-institutional, collaborative research initiative is a common nomenclature.<sup>92,94</sup> In the past decade, a group of international experts in the fields of pediatric cardiology, cardiac surgery, pediatric cardiac anesthesia, pediatric cardiac critical care, morphology, and pathology has created the International Pediatric and Congenital Cardiac Code (IPCCC; www.ipccc.net).<sup>48-52,57,92,94</sup> The IPCCC is currently used in the majority of multi-institutional databases in the world that relate to pediatric and congenital cardiac disease.

We hypothesize that the IPCCC will become more useful, global, and powerful by associating the terms in the IPCCC with images and video. Therefore, the overall goal of this article is to describe a project that has created a Web-based platform that illustrates the codes and definitions of the IPCCC with images in a variety of formats. These formats include photographs of pathologic specimens; images and video clips from multiple imaging modalities such as echocardiograms, angiograms obtained by cardiac catheterization,

computerized axial tomography scans, and magnetic resonance imaging (MRI); and intraoperative photographs and videos of surgical interventions.

### *Background of the International Society for Nomenclature of Paediatric and Congenital Heart Disease*

A modern, international, classification of the various forms of heart disease that affect children, based on logic and the best available science, is important and of great value for those involved in the care and treatment of pediatric patients with acquired and congenital cardiac diseases. This system of classification is needed to modernize our understanding of the evolving natural histories and to evaluate the outcomes of treatments and interventions across national barriers.

During the 1990s, both the European Association for Cardio-Thoracic Surgery (EACTS) and the Society of Thoracic Surgeons (STS) created databases to assess the outcomes of congenital cardiac surgery. Beginning in 1998, these 2 organizations collaborated to create the International Congenital Heart Surgery Nomenclature and Database Project. On September 19, 1998, the International Congenital Heart Surgery Nomenclature and Database Project, chaired by Constantine Mavroudis and Jeffrey P. Jacobs, was created to address the need for standardization of nomenclature and database definitions in the field of congenital heart surgery. A common nomenclature, along with a common core minimal data set, was

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adopted by the STS and EACTS and published in 2000 in the *Annals of Thoracic Surgery*.<sup>5</sup>

In 2000, almost simultaneously with the publication of the nomenclature of the International Congenital Heart Surgery Nomenclature and Database Project described above, the Association for European Paediatric Cardiology (AEPC) also published a nomenclature system named the European Paediatric Cardiac Code (EPCC).<sup>145</sup> Members of the AEPC, EACTS, and STS rapidly realized that these 2 nomenclature systems were complementary and not competitive. Therefore, in Frankfurt, Germany, on October 6, 2000, at a meeting attended by representatives of the AEPC, EACTS, and STS, as well as multiple other societies, the International Nomenclature Committee for Pediatric and Congenital Heart Disease was founded; this committee eventually evolved into the International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPCHD).

Both the nomenclature system devised by the International Congenital Heart Surgery Nomenclature and Database Project and that suggested by the AEPC include a Short List and a Long List. The Short List facilitates the creation of multi-institutional outcomes registries. The Long List supports the creation of echocardiographic software, academic databases, and the electronic medical record. A cross-map of the Short Lists was presented at the First International Summit on Nomenclature for Congenital Heart Disease at the Third World Congress of Pediatric Cardiology and Cardiac Surgery, in Toronto, Canada, on May 27, 2001, and was subsequently published.<sup>48-52,57,92,94</sup>

At the First International Summit on Nomenclature for Congenital Heart Disease, the Nomenclature Working Group (NWG) was created. The NWG has been the primary working component of the ISNPCHD. By 2005, the NWG had nearly completed the cross-map between the nomenclature of the Long List of the International Congenital Heart Surgery Nomenclature and Database Project of the EACTS and the STS with the Long List of the EPCC of the AEPC, and therefore created the International Pediatric and Congenital Cardiac Code (IPCCC), which is available for free download from the Internet at [www.ipccc.net](http://www.ipccc.net). The IPCCC and cross-map of the Long Lists were presented at the Second International Summit on Nomenclature for Pediatric and Congenital Heart Disease at the Fourth World Congress of Pediatric Cardiology and Cardiac Surgery, in Buenos Aires, Argentina, on September 19, 2005. The current version of the IPCCC was presented at the Third International Summit on Nomenclature for Pediatric and Congenital Heart Disease at the Fifth World Congress of Pediatric Cardiology and Cardiac Surgery, Cairns, Australia, on June 21, 2009.

The IPCCC is mapped to the following systems of nomenclature:

1. The International Congenital Heart Surgery Nomenclature and Database Project of the EACTS and the STS
2. The EPCC of the AEPC
3. The Fyler Codes of Boston Children's Hospital and Harvard University

4. The *International Classification of Diseases (ICD-9 and ICD-10)* administered by the World Health Organization
5. The Current Procedural Terminology

The NWG has also cross-mapped separate systems for coding and provided unified nomenclature and definitions for several complex congenital cardiac malformations, including the functionally univentricular heart,<sup>73</sup> hypoplastic left heart syndrome,<sup>75</sup> congenitally corrected transposition,<sup>76</sup> and heterotaxy.<sup>83</sup>

The IPCCC is available free of charge via the Internet ([www.ipccc.net](http://www.ipccc.net)). At the IPCCC Web site, one may download the Short Lists and Long Lists of the IPCCC. Three versions of the IPCCC are available:

1. The version of the International Pediatric and Congenital Cardiac Code derived from the nomenclature of the International Congenital Heart Surgery Nomenclature and Database Project of the EACTS and the STS
2. The version of the International Pediatric and Congenital Cardiac Code derived from the nomenclature of the EPCC of the AEPC
3. The version of the International Pediatric and Congenital Cardiac Code derived from the nomenclature of the Fyler Codes of Boston Children's Hospital and Harvard University

The version of the IPCCC derived from the nomenclature of the International Congenital Heart Surgery Nomenclature and Database Project of the EACTS and the STS has been used in a variety of settings, including the following research studies:

1. A multi-institutional study of functionally single ventricles via the Pediatric Heart Network
2. The Centers for Disease Control and Prevention birth surveillance research study in which the Metropolitan Atlanta Congenital Defects Program reclassified more than 11 000 patients according to this version of the IPCCC
3. A National Institutes of Health–funded initiative examining the relationship of air pollution to the development of congenital cardiac malformations in the fetus (R01ES012967)
4. The National Institutes of Health–funded multicenter, randomized trial, conducted by the Pediatric Heart Network, that compares outcomes in patients with hypoplastic left heart syndrome, or other functionally univentricular hearts of right ventricular morphology, who are randomized to the Norwood stage 1 operation with either a modified Blalock-Taussig systemic-to-pulmonary artery shunt or a right ventricular to pulmonary arterial shunt
5. The Pediatric and Congenital Cardiothoracic Surgical Databases of the EACTS and the STS use the version of the IPCCC derived from the nomenclature of the International Congenital Heart Surgery Nomenclature and Database Project of the EACTS and the STS. Between 1998 and 2009 inclusive, this nomenclature was used by both

**Table 1.** Members of the Archiving Working Group (AWG)**Co-chairpersons**

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**International Society for Nomenclature of Paediatric and Congenital Heart Disease Executive Committee**

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Diane Spicer (Cardiac Morphologist, USA)

of these organizations to analyze outcomes of more than 200 000 operations involving patients undergoing surgical treatment for pediatric and congenital cardiac disease.

In Europe, the version of the IPCCC derived from the nomenclature of the EPCC of the AEPC has also been used in a variety of settings, including the following projects:

1. In the United Kingdom, the United Kingdom Central Cardiac Audit Database uses the Short Lists from the version of the IPCCC derived from the nomenclature of the EPCC of the AEPC as the basis for its national, comprehensive, validated, and benchmark-driven audit of all pediatric surgical and transcatheter procedures undertaken since 2000
2. In Germany, internal quality control for all centers is based on the version of the IPCCC derived from the nomenclature of the EPCC of the AEPC. The Nationale Register für angeborene Herzfehler in Berlin also uses the version of the IPCCC derived from the nomenclature of the EPCC of the AEPC for coding all patients with congenital heart disease. In addition, the Kompetenznetz angeborene Herzfehler also uses this version for a nationwide scientific network supported by the German government for various specific studies, such as on right ventricular function, pulmonary hypertension, tetralogy of Fallot, and interatrial communication

3. In the Netherlands, the national registry of congenital heart disease, CONCOR (Congenital Corvitia), uses the version of the IPCCC derived from the nomenclature of the EPCC of the AEPC
4. The Swiss Paediatric Cardiology Society uses the version of the IPCCC derived from the nomenclature of the EPCC of the AEPC for quality control between centers

This common nomenclature, the IPCCC, is now used in multiple subspecialty databases that involve the professionals caring for patients with congenital cardiac disease. Each of these database systems employs the IPCCC and is at varying stages of development:

1. Pediatric and congenital cardiothoracic surgery under the leadership of the EACTS and the STS, as well as several national database initiatives such as the United Kingdom Central Cardiac Audit Database (UKCCAD)
2. Pediatric and congenital cardiology under the leadership of the American College of Cardiology and the Association for European Paediatric Cardiology, as well as several national database initiatives such as the UKCCAD
3. Pediatric and congenital cardiac anesthesia under the leadership of the Congenital Cardiac Anesthesia Society
4. Pediatric and congenital cardiac critical care under the leadership of the Pediatric Cardiac Intensive Care Society

In July 2007, the ISNPCHD created 2 new committees so that the ISNPCHD now has the following 3 committees with complementary responsibilities:

- A. The International Working Group for Mapping and Coding of Nomenclatures for Paediatric and Congenital Heart Disease, also known as the Nomenclature Working Group (NWG)
- B. The International Working Group for Defining the Nomenclatures for Paediatric and Congenital Heart Disease, also known as the Definitions Working Group (DWG)
- C. The International Working Group for Archiving and Cataloguing the Images and Videos of the Nomenclatures for Paediatric and Congenital Heart Disease, also known as the Archiving Working Group (AWG)

The NWG will continue to maintain, preserve, and update the IPCCC, as well as provide ready access to it for the international pediatric and congenital cardiology and cardiac surgery communities, related disciplines, the health care industry, and governmental agencies, both electronically and in published form.

The DWG will write definitions for the terms in the IPCCC, building on the previously published definitions from the NWG.<sup>73,75,76,83</sup>

The AWG will enable the linkage of images and videos to the IPCCC. The images and videos will be acquired from cardiac morphologic specimens and imaging modalities such



**Figure 1.** Homepage of the Archiving Working Group (AWG) Web Portal Project. Figures 1 through 4 are examples of the AWG Web Portal (<http://ipccc-awg.net>). Navigation is sequential from Figure 1. This figure illustrates the homepage and gives a brief overview of the AWG Web Portal Project and also displays the “Featured Submission.” The user selects the “Images & Codes” tab to begin the navigational process. In addition, the “Navigation Bar” gives the user the capacity to submit an image (“Submissions”) or view other features of the AWG Web Portal.

as echocardiography, angiography, computerized axial tomography, and magnetic resonance imaging (MRI), as well as intraoperative images and videos.

The mandate of the AWG is to link images of all types to the codes of the IPCCC and the definitions provided by the DWG. The images and videos reflect a variety of modalities, including photographs of gross anatomic specimens, echocardiograms, angiocardiograms, computerized axial tomography, and magnetic resonance images, as well as intraoperative photographs and videos. The AWG currently has an active image and video archive that is named the Archiving Working Group Web Portal and is based on the IPCCC. This “online encyclopedia,” linked to the codes and the associated definitions, may be viewed at the AWG Web Portal at <http://ipccc-awg.net>. The intended audience of the AWG Web Portal is the medical community with an interest in acquired and congenital cardiac lesions. It is an open site that is accessible to all.

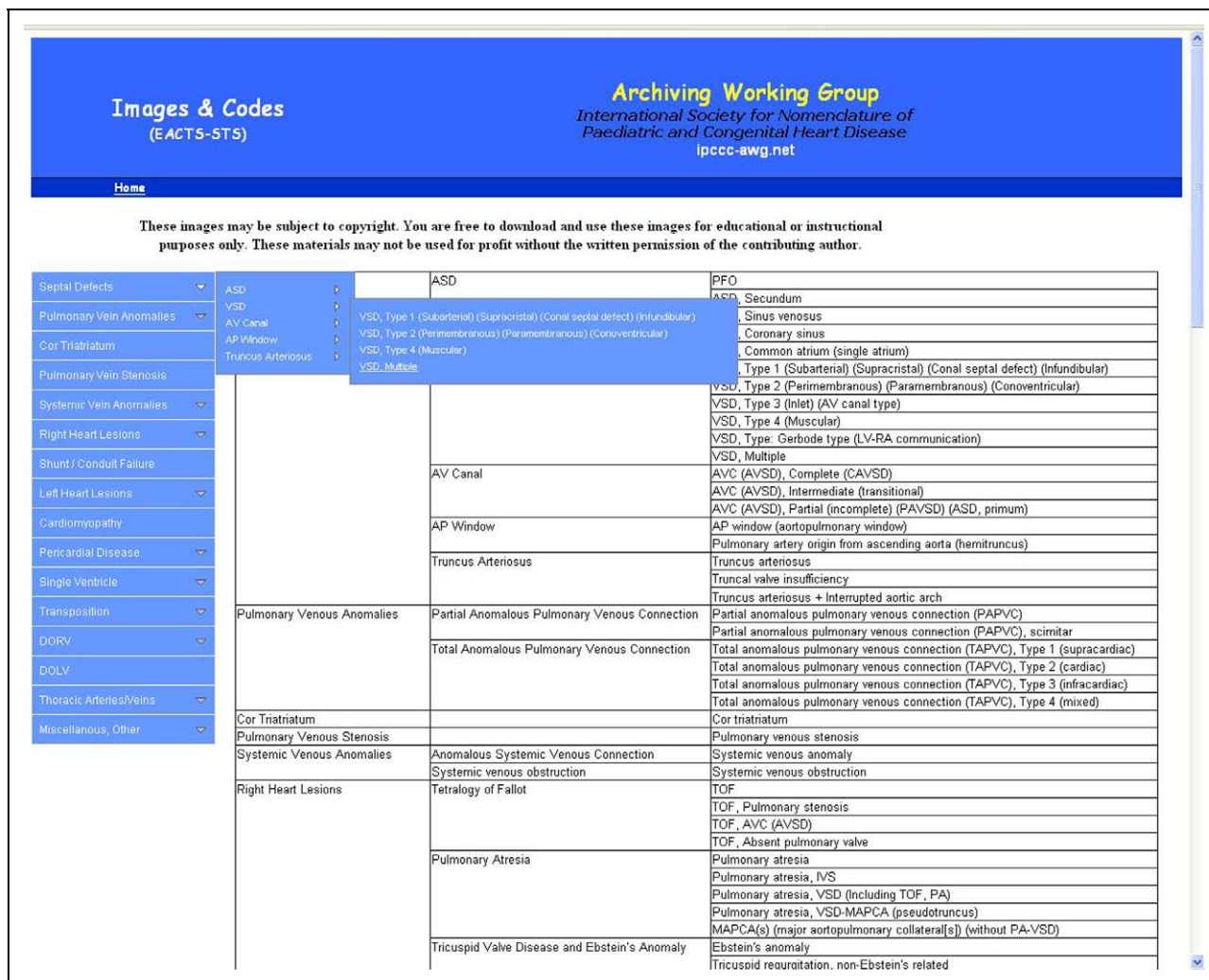
## Results

### *Creation of a Prototype Web-Based Visual Encyclopedia Illustrating the Terms and Definitions of the IPCCC*

The AWG has developed a prototype Web site (<http://ipccc-awg.net>) where the IPCCC codes and definitions are listed and representative images are posted. This prototype portal is named the Archiving Working Group Web Portal Project (AWG Web Portal). The AWG Web Portal provides preliminary evidence of the feasibility of this project and demonstrates the potential of this initiative.

The AWG Web Portal workflow structure follows a similar process to a peer-reviewed publication. The members of the AWG (Table 1) share the responsibility of submitting and identifying suitable images from their institutional and daily clinical activity. Alternatively, images may be directly submitted to the AWG Web Portal by members of the medical community





**Figure 2.** Navigation of the Archiving Working Group (AWG) Web Portal Project. Figure 2 continues the sequence and illustrates the “Images & Codes” section, which allows the user to navigate to the “entry page.” This entry page is organized using the Short Lists of either the Association for European Paediatric Cardiology (AEPC) or the European Association for Cardio-Thoracic Surgery–Society of Thoracic Surgeons (EACTS-STs) nomenclature system. It is structured so that the various images and International Pediatric and Congenital Cardiac Code (IPCCC) codes fall under a particular category of the Short Lists. In this example, using the EACTS-STs structure, “Septal Defects” leads to “VSD,” which in turn takes the user to the “VSD, Multiple” entry page.

interested in this project. During the process of image submission, the contributing author confirms that consent has been obtained from the patient or guardian to share the images with the AWG Web Portal. The contributing author is solely responsible for obtaining this consent. All images (and accompanying textual information) respect patient privacy and are free of patient identification. If the image submitted retains identification characteristics, these are removed before posting to the Web site. Subsequently, the senior archivist links these images to the IPCCC and catalogues and archives them. After the initial identification and assignment process is completed, a Web page for the particular IPCCC code is created or modified, and the images, codes, definitions and explanatory text are posted to the AWG Web Portal. The initial publication of the images to the AWG Web Portal is labeled “Pending Certification.” On a periodic basis, the members of the AWG review the posted

images, codes, and text for accuracy, quality, and suitability. After this process is completed, the posted images, if approved, receive the official certification, and the Web page is updated to reflect the date of final approval. Using this approach, the IPCCC codes are not only textually described and defined but also illustrated by the use of images and videos. The certification of the images by an international panel of experts, as well as the linking to the IPCCC codes and definitions, confirms the validity of the IPCCC. This collection of images and videos helps to remove ambiguity of the terms used in the IPCCC and the associated definitions.

The AWG Web Portal is the only cohesive, organized effort to link images and videos to the IPCCC. The AWG Web Portal structure is a menu-driven unidirectional navigational system based on the IPCCC Short Lists of the EACTS-STs and the EPCC of the AEPC. To navigate the Web site, the user selects



**Figure 3.** Entry Page of the Archiving Working Group (AWG) Web Portal Project. Figure 3 illustrates the entry of the user into each subcategory that has images posted. This example illustrates the choices available under the European Association for Cardio-Thoracic Surgery–Society of Thoracic Surgeons (EACTS-STS) Short List Diagnostic Term of “VSD, Multiple.” The user clicks on the image that illustrates the International Pediatric and Congenital Cardiac Code (IPCCC) code of interest. This takes the user to the page where the images with codes and definitions are posted.

from drop-down menus to reach the areas of interest. For example, using the EACTS-STS Short List structure, one can select {Septal Defects > VSD > VSD, Multiple} to reach the subpage where images representing various types of multiple ventricular septal defects are listed. The user clicks on the image, and IPCCC codes are displayed, along with any associated images, video, and explanatory text.

The images and videos reflect a variety of modalities, including photographs of autopsy or intraoperative specimens, short video clips of echocardiograms, angiocardiograms, computerized axial tomography, and magnetic resonance studies, as well as surgical interventions. The contributions are catalogued and stored in an offline image archive, using industry standard formats, and databases using the IPCCC codes as the mechanism of organization. The creation of the Web pages also follows a similar format. The rationale is the maintenance of flexibility and the capacity to adapt to future changes in technology.

Although the images displayed may have copyright obligations, a unique feature of the AWG Web Portal is that the contributing author has given permission for the portal visitor to download the images and use them for not-for-profit, instructional, or educational purposes. At present, the AWG Web Portal has over 50 finished subpages with more than 100 images. These pages have been preliminarily catalogued and are pending

certification. In large part, progress has occurred in 2009 due to the increased efforts of the senior archivist, who has been able to work on a part-time basis on the AWG Web Portal.

Figures 1 through 4 illustrate the process using images from the AWG Web Portal. Multiple additional images may be viewed at the AWG Web Portal (<http://ipccc-awg.net/>).


## Comment

The AWG of the ISNPCHD has created a Web-based archive of representative images that visually define the codes and textual definitions of the IPCCC. The goal of the ISNPCHD is “to standardize and maintain an international nomenclature system to enhance global communication and facilitate patient care, teaching, and research into pediatric and congenital heart disease across disciplines.”<sup>146</sup> Conceptually, as developed by the members of the ISNPCHD,<sup>94</sup> the Society has aimed to follow these qualifications in its development of the IPCCC:

- A structure capable of expressing simple and complicated concepts, sensitive to clinical structure and use
- The capacity to stratify risk

Images & Codes

**Archiving Working Group**  
*International Society of Nomenclatures for  
Paediatric and Congenital Heart Disease*  
ipccc-awg.net



**IPCCC Code: 07.15.04, 07.11.05, 07.10.01, 07.13.05, 01.01.18**

**AEPC Code:** Multiple VSDs, Muscular VSD: multiple trabecular (Swiss cheese), Perimembranous VSD, VSD in double outlet VA connection: subpulmonary, Double outlet right ventricle: transposition type (subpulmonary VSD)

**FACTS-STIS Code:** VSD, Multiple, VSD, Type 4 (Muscular), Multiple - "Swiss-Cheese", VSD, Type 2 (Perimembranous) (Paramembranous) (Conoventricular), VSD-modifier, VSD in double outlet VA connection, Subpulmonary, DORV, "TGA type" (Subpulmonary VSD)

**Definition:** NA

**Common Synonyms:** NA



The outlet components and septal surface of this heart with double outlet right ventricle are viewed from the apex. The aorta (A) is anterior and to the right of the pulmonary trunk (PT). The aortic valve (AV) is supported by a complete muscular infundibulum and



The left ventricle of the heart shown in the left panel is opened in a clam-shell fashion demonstrating the perimembranous ventricular septal defect (PMVSD) and the multiple, apical, muscular ventricular septal defects (MVSD). The mitral valve (MV) guards the inlet of

**Figure 4.** Image & Code page of the Archiving Working Group (AWG) Web Portal Project. Figure 4 is an example of the format for display of a completed page with images, codes, and, when available, definitions. The user may select an image within this page, and the full-resolution image will be displayed for review or download for not-for-profit use. In addition, this process also allows for the viewing of videos in motion. Although not displayed in this figure, the “Certification” status is listed at the bottom of the page. Once reviewed and certified by the AWG Editorial Board, the date of certification is added.

- The standardization of terms and classifications across specialties
- The capacity to integrate synonyms and commonly used abbreviations with preservation of a preferred phenotypic expression, as well as the capacity to express “diagnostic uncertainty” or “negative” findings
- The ability to find appropriate terms by different pathways and in multiple languages
- The capacity to update or modify the nomenclature and definitions in the IPCCC (including obsolete or inaccurate concepts) based on scientific or procedural advances
- The “certification” of terms, definitions, and images by a group of experts in congenital and acquired pediatric heart disease

The ISNPCHD has developed a system of nomenclature for multiple uses, including clinical, research, educational, and

administrative purposes. The creation of a Web-based “encyclopedia” to visually illustrate the terms and definitions of the IPCCC helps to further this goal. It also supports the element of international inclusion because the AWG Web Portal is truly worldwide, and the images and contributions to this project are open to all regardless of geographical barriers. The use of an international body of certifying experts lends uniformity and representation to the process.

The AWG Web Portal has created a Web-based visual encyclopedia illustrating the terms and definitions of the IPCCC, the system of nomenclature developed by the ISNPCHD. Imagine a Web site that allows a visitor to select a diagnosis and view virtual images of hearts with that diagnosis in multiple modalities, including a photograph of the morphological specimen, echocardiogram, angiogram, and intraoperative specimen.

The AWG Web Portal has created a structure that supports education and future research in multiple domains. The Web



site is free to access, and it is hoped that it will increase the universal understanding and utilization of the IPCCC.

Multi-institutional collaboration can lead to advances in patient care, research, teaching, and even service (by providing health care to those in developing nations). All of these domains of multi-institutional collaboration are based on the foundation of a common language or nomenclature. The IPCCC is a universal nomenclature of pediatric and congenital heart disease. By linking the IPCCC to pictures and videos and making these linked images and videos widely available, this project will make the IPCCC more accessible and universal.

We encourage the readers of this article to visit the AWG Web Portal (<http://ipccc-awg.net>) and contribute their images and thoughts.

### Declaration of Conflict of Interests

The authors declared a potential conflict of interest (eg, a financial relationship with the commercial organizations or products discussed in this article) as follows: Jeffrey P. Jacobs, MD, is the medical director of CardioAccess, Inc.

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