Illustrating Terms in Lists of Nomenclature

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Abstract

Survival for children with cardiac disease has dramatically increased in the past four decades with the advent of improvements in diagnosis and treatment. In order to further decrease morbidity and mortality, optimization of outcomes must be vigorously pursued, and this optimization requires a common language when discussing and comparing results of the available diagnostic and therapeutic options. This common language exists and is named The International Pediatric and Congenital Cardiac Code (IPCCC). In order to make the IPCCC more universally understood, a 'virtual visual encyclopedia' has been created that links and illustrates the terms and definitions of the IPCCC with images of all types. The Archiving Working Group (AWG) of the International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPCHD) is an organization composed of members of the international pediatric cardiac medical and surgical community that collaborate to illustrate, with representative images of all types and formats, the pertinent aspects of cardiac diseases that affect all pediatric patients, using the codes and definitions of the IPCCC as the organizational structure. This chapter describes

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the process of linking illustrations and nomenclature in the effort to better understand congenital and acquired cardiac disease and improve outcomes.

Keywords

Databases • Cardiac nomenclature • Illustrations • Congenital heart disease • Internet • Cardiac encyclopedia • Cardiac images • International Pediatric and Congenital Cardiac Code

Abbreviations

AEPC	Association for European Paediatric Cardiology
AWG	Archiving Working Group
CPT	Current procedural terminology
DWG	Definitions Working Group
EACTS	European Association for Cardio-Thoracic Surgery
ICD	The International Classification of Diseases
IPCCC	International Pediatric and Congenital Cardiac Code
ISNPCHD	International Society for Nomenclature of Paediatric and Congenital Heart Disease
JPEG	Joint Photographic Expert Group
MRI	Magnetic resonance imaging
NWG	Nomenclature Working Group
STS	Society of Thoracic Surgeons

Introduction

Attempts to understand, classify, and illustrate the various medical afflictions of mankind have been part of the human legacy from the earliest days of recorded antiquity. The best well documented of these histories come from the Greco-Roman world and were reintroduced into Western Europe at the time of the 'Golden Age' of Arabic-Islamic science [1]. The intellectual ferment of the Renaissance changed the prevalent static nature of medical thinking and encouraged the approach of direct observation. This process slowly changed the philosophical underpinnings of learning and practicing medicine, from the study of the writings of Galen to that of empirical observations. As the study of normal and pathologic anatomy grew from isolated instances to the systematic review of the available pathologies, catalogues or atlases linking illustrations with the prevailing terms grew in importance and availability. In the modern era, this phenomenon has become even more important; and now, terms of nomenclature, describing the diagnosis and treatments for the diverse forms of cardiac disease, and based on logic and the best available science, have become the standard way to classify and catalogue the diverse manifestations of cardiac disease of neonates, infants, children, and young adults. As discussed in previous chapters, the International Pediatric and Congenital Cardiac Code (IPCCC) is one of the most commonly used international systems of nomenclature for cardiac disease. The IPCC was copyrighted in 2005 by the International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPCHD) and is freely available for download at http://www.ipccc.net/. The IPCCC consists of a cross-map linking the following systems of classification:

1. The International Congenital Heart Surgery Nomenclature and Database Project of the European Association for Cardio-Thoracic Surgery (EACTS) and the Society of Thoracic Surgeons (STS).
2. The European Paediatric Cardiac Coding (EPCC) of the Association for European Paediatric and Congenital Cardiology (AEPC).
3. The Fyler Codes of Boston Children's Hospital and Harvard University.
4. The International Classification of Diseases (ICD-9 and ICD-10) of the World Health Organization.

5. The Current Procedural Terminology (CPT) of the American Medical Association.

As one of the three working groups of the ISNPCHD, the Archiving Working Group (AWG) was formed in 2007 with the mandate of using images and illustrations to complement the written codes and definitions available within the IPCCC. The AWG became operational in 2010 with the development of a process and web presence (ipccc-awg.net) that strives to identify, certify, and display images in all formats, of the best available phenotypes that illustrate the list of terms of the IPCCC. Therefore, the purpose of this chapter is to discuss the process followed by the AWG and the lessons learned on how to develop a comprehensive system of illustrations of nomenclatures. This effort is in keeping with the ultimate goal of the authors, in promoting the use of a universal system of nomenclature that facilitates the large scale adoption of pediatric cardiac databases. The long term effect will be to improve communications between all pediatric cardiac specialties and promote continued advancements in the diagnosis and treatment of the neonate, infant, child, and young adult with the various forms of pediatric and congenital cardiac disease.

Historical Background

Hippocrates of Kos (460–370 BCE) is credited with being the first reject the widely held belief of the divine origin of disease and to argue for the practice of medicine based on observation and rational thought. "On Fractures" as well as in other treatises and part of the Hippocratic Corpus (a collection of writings ascribed to Hippocrates but with likely contributions by others), reflected a significant body of knowledge of anatomy that could only be gained by direct observations on the human body [2, 3]. In Hellenistic Alexandria, Herophilos (280 BCE) began the systematic use of dissections on human cadavers to study anatomy; and as this knowledge advanced, illustrations were used to help in the teaching of this new found knowledge [4–6]. Galen (129–200 CE), the most famous physician of Roman times, and personal doctor to the emperors Marcus Aurelius, Commodus and Septimus Severus, was born in Pergamun in Asia Minor. Galen was the intellectual heir to the Greek traditions of medicine, wrote profusely on many subjects, including philosophy, and understood the relationship between anatomy and physiology. Unfortunately, due to the Roman prohibition of human dissections, Galen performed his anatomical studies almost exclusively on animals, principally the pig and Barbary ape. He wrote many of his works on the various aspects of medicine, and by some accounts his literary output was in the order of as many as 400–600 manuscripts. Some of his works were illustrated to complement his concepts and descriptions of health and disease, based on the Hippocratic humoral theory of disease. Sadly most of his manuscripts were destroyed in a fire a few years before his death [7, 8]. The assumptions made by Galen in conjunction with the social and religious changes that occurred after the fall of the Western Roman Empire went unchallenged until the Renaissance and the advent of the rebirth in the study of human diseases and their classification.

It is suggested that the great Renaissance artists such Raphael and Michelangelo performed their own dissections. However, it was Leonardo da Vinci (1452–1519 CE) who, in order to understand and improve his renditions of the human body, performed as many as thirty (30) dissections in his study of human anatomy. Nevertheless it is understood that da Vinci's interest was primarily artistic, a means to 'perfect' the anatomical detail of his paintings and sculptures [6]. These innovations by Leonardo da Vinci, paved the way for Andreas Vesalius (1514–1564 CE) epic study of the human body, 'De Humani Corporis Fabrica Libri Septem' (1543). This document is likely one of the most important and influential anatomical medical works ever published, because it not only reflected Vesalius' careful, direct observations based on his own dissections, but also on the artistry of the 186 illustrations that accompanied his descriptions. Vesalius' observations rejected and in other cases confirmed many of Galen's

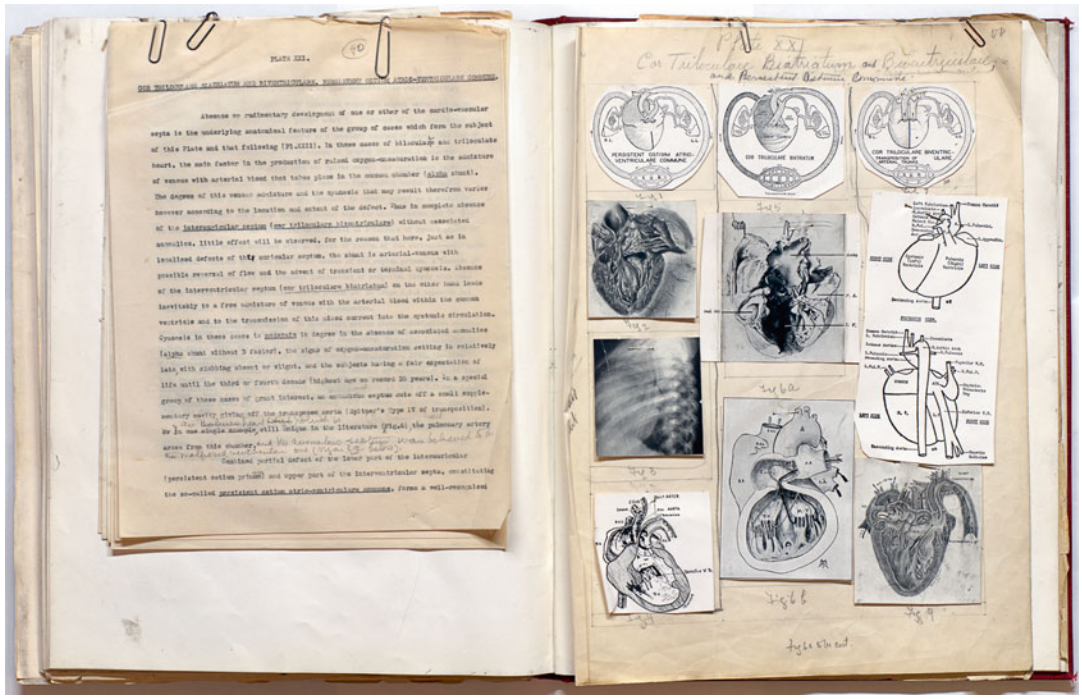

Fig. 7.1 This is a photograph of a draft copy of Maude Abbott's Atlas that was given by Lois Hawkins of the Division of Paediatric Cardiology in Edmonton, Canada to the Osler Library at McGill University in 2008 (Reproduced by permission of the Osler Library of the History of Medicine, McGill University)

observation and theories. For his investigations and publications, Vesalius received both condemnation and praise. He became court physician to Charles V, Holy Roman Emperor, and traveled throughout many parts of Europe. He died in 1564 following a shipwreck on the Greek island of Zante, after returning from a pilgrimage to Jerusalem, and on his way to Padua where he had been appointed to a prestigious chair in anatomy [5, 7–10].

The seventeenth and eighteenth centuries saw an increase in the interest of defining and illustrating the diverse forms of cardiac disease and saw anecdotal contributions from well known figures in the history of medicine such as LeCat, Morgagni and Hunter. The nineteenth century saw contributions by Farre, Gintrac, Meckel and Paget, as well as Fallot [11]. In 1858, Thomas Peacock published his book 'On Malformations of the Human Heart', where he outlined a system of classification based on cardiac anatomy and embryology. This book was the outgrowth of a series of lectures given to students at St. Thomas Hospital [12]. Then, in 1875, Carl von Rokitansky published his 'Defects of the Cardiac Septa' (Die Defekte der Scheidewände des Herzens) [13]. As curator of the McGill Medical Museum and inspired by Sir William Osler, Maude Abbott, in 1901, published an article in the Montreal Medical Journal of a congenitally malformed heart given to McGill University by Andrew Holmes, one of the founders of the McGill Medical School, in 1823. Abbott's work with congenitally malformed hearts proved to be the most important aspect of her academic career [14]. In 1936, she published the Atlas of Congenital Cardiac Diseases (Fig. 7.1), which consisted of 75 pages with 25 illustrated plates, grouped under her system of classification [15]. Dr. Abbott's work can be considered the "first systematic classification of congenital cardiac lesions" [16]. In 1947, Helen Taussig published her two volume book "Congenital Malformations of the Heart" [11]. The last half of the twentieth

century saw the contributions to the understanding of congenital cardiac morphology by Maurice Lev, Jesse Edwards, Richard and Stella Van Praagh, Robert Anderson and Anton Becker, among others. At this time, systems of classification were neither uniform nor universal, but Van Praagh and Van Praagh and coworkers, as well as Anderson and colleagues, proposed different systems of classification and organization based on a segmental approach. These two systems were in some ways similar, but they were different enough that two competing systems developed and were used separately or in combination by different practitioners and institutions [17].

In a parallel effort, the pediatric cardiac surgeons were also developing additional systems of nomenclature for use in the coding of cardiac surgical diagnoses and procedures. Fortunately, by the first decade of the twenty-first century, developments within the pediatric cardiology and pediatric cardiac surgical community led to the recognition that a universal and comprehensive system of nomenclature was within reach. In 2000, representatives from The Association for European Paediatric Cardiology (AEPC), The Society of Thoracic Surgeons (STS), and The European Association for Cardio-Thoracic Surgery (EACTS), as well as other societies and entities, agreed to establish The International Nomenclature Committee for Pediatric and Congenital Heart Disease, which later became The International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPCHD). In 2001, at The First International Summit on Nomenclature for Pediatric and Congenital Heart Disease held at The Third World Congress of Pediatric Cardiology and Cardiac Surgery in Toronto, Canada, the Nomenclature Working Group (NWG) of The International Nomenclature Committee for Pediatric and Congenital Heart Disease was established. The initial goal of the NWG was to work in partnership and produce a reconciliatory bidirectional map between the predominant nomenclature systems for pediatric and congenital cardiac disease; this bidirectional map and system of nomenclature was ultimately named The International Pediatric and Congenital Cardiac Code (IPCCC) [16]. By 2005, the NWG had nearly completed the cross-map and presented the results at The Second International Summit on Nomenclature for Pediatric and Congenital Heart Disease held at The Fourth World Congress of Pediatric Cardiology and Cardiac Surgery in Buenos Aires, Argentina. In 2009, an updated version of the IPCCC was presented at The Third International Summit on Nomenclature for Pediatric and Congenital Heart Disease held at The Fifth World Congress of Pediatric Cardiology and Cardiac Surgery in Cairns, Australia. In 2013, an additional updated version of the IPCCC was presented at The Fourth International Summit on Nomenclature for Pediatric and Congenital Heart Disease held at The Sixth World Congress of Pediatric Cardiology and Cardiac Surgery in Cape Town, South Africa.

In 2007, in a parallel development, the ISNPCHD created two additional Working Groups, so that the ISNPCHD now has the following three committees or working groups [18–25]:

1. The Nomenclature Working Group (NWG) was created in 2001 and is the oldest and original working group of the ISNPCHD. The purpose of the NWG is to maintain, develop, expand, update, and preserve the IPCCC. It also has the ancillary responsibility to provide ready access to the IPCCC for the global pediatric and congenital cardiology and cardiac surgery communities as well as related disciplines and interested parties and individuals. The IPCCC is available free of charge from the Internet at http://www.ipccc.net/.
2. The Definitions Working Group (DWG) was created in 2007. The purpose of the DWG is to write definitions for the terms in the IPCCC, building on the previously published definitions from the Nomenclature Working Group.
3. The Archiving Working Group (AWG) was also created in 2007. The purpose of the AWG is to link images and videos of all types to illustrate the terms and definitions of the IPCCC. The images and videos may be from cardiac morphologic specimens as well as a variety of other sources including

echocardiograms, angio-cardiograms, computerized axial tomographic images, magnetic resonance images, and intra-operative images and videos.

Illustration of the Terms of the IPCCC

In the effort to illustrate, with representative images, the terms and definitions of the IPCCC, the AWG has developed and maintains an active web presence known as the Archiving Working Group Web Portal, which may be accessed at http://www.ipccc-awg.net/. The remainder of this chapter will review the organization of the AWG Web Portal and the lessons that have been learned in the process of promoting and illustrating the lists of terms and definitions that compose the IPCCC.

1. **AWG Organization:**
   - 1.1. AWG Workflow: The workflow structure follows a peer-reviewed process. The identification of images, with accompanying textual explanations, may be solicited or unsolicited. The members of the AWG project (Table 7.1), and in particular the Senior Archivist, share in the responsibility of identifying the images that illustrate the codes and definitions of the IPCCC. The Senior Archivist and the three Co-Chairpersons of the AWG work closely during the initial review and assignment of the codes and definitions to the images identified and submitted. After the process is completed, a web page is created or modified, and the images, codes, definitions, and explanatory text are posted to the internet presence of the AWG called the AWG Web Portal. The initial publication of the images to the AWG Web Portal is posted with the label: "Pending' certification".
   - 1.2. Review Process: On a periodic basis, typically every other month, the members of the AWG review the posted images, codes, and text for accuracy, quality, and suitability. The typical review process is carried out trans-telephonically using an international call center and a specially created; internet based, closed 'wiki' [26]. The participants of the conference are able to view the images and posted comments on their computers while discussing the images and terms by telephone. The suggestions are incorporated into the 'wiki' concurrently in real time

Table 7.1 Members of the Archiving Working Group

Co-chairpersons
Vera D. Aiello (Cardiac Pathologist, Brazil)
Robert H. Anderson (Cardiac Morphologist, UK and USA)
Jorge M. Giroud (Pediatric Cardiologist, USA)
ISNPCHD executive committee
Rodney C. G. Franklin (Pediatric Cardiologist, UK) (President, NWG Co-Chair)
Jeffrey P. Jacobs (CV Surgeon, USA) (Vice President, NWG Co-Chair)
Christo I. Tchervenkov (CV Surgeon, Canada) (Past President)
Marie J. Béland (Pediatric Cardiologist, Canada) (NWG Co-Chair)
Steven D. Colan (Pediatric Cardiologist, USA) (DWG Co-Chair)
Henry Walters III (CV Surgeon, USA) (DWG Co-Chair)
Editorial members
Carl Backer (CV Surgeon, USA)
Frederique Bailliard (Pediatric Cardiologist, USA)
Meryl Cohen (Pediatric Cardiologist, USA)
Andrew Cook (Cardiac Morphologist, UK)
Allen D. Everett (Pediatric Cardiologist, USA)
J. William Gaynor (CV Surgeon, USA)
Lucile Houyel (Pediatric Cardiologist, France)
Marina Hughes (Pediatric Cardiologist/MRI, UK)
Marshall L. Jacobs (CV Surgeon, USA)
Amy Juraszek (Pediatric Cardiologist, USA)
Otto N. Krogmann (Pediatric Cardiologist, Germany)
Hiromi Kurosawa (CV Surgeon, Japan)
Leo Lopez (Pediatric Cardiologist, USA)
James St. Louis (CV Surgeon, USA)
Bohdan Maruszewski (CV Surgeon, Poland)
Charles Shepard (Pediatric Cardiologist, USA)
Giovanni Stellin (CV Surgeon, Italy)
Paul M. Weinberg (Pediatric Cardiologist/ Morphologist, USA)
Senior Archivist
Diane Spicer (Cardiac Morphologist, USA)

Fig. 7.2 Home (Landing) Page of the AWG Web Portal (http://ipccc-awg.net). This figure illustrates the homepage and gives a brief overview of the AWG Web Portal. Please note the Navigation Bar that gives the user the capacity to review and image or video, submit an image or video, or view other features of the AWG Web Portal such as our sponsors and membership of the AWG. This home page is linked to the website of The International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPCHD): http://www.ipccc.net/

and immediately updated. This process ensures a timely and simultaneous review of the images linked to the corresponding terms and definitions of the IPCCC. After the evaluation of the posted image is completed, the images with the accompanying web page are officially certified and rated on a scale of 1–4 hearts, with four hearts being a superb example of the phenotype encoded by the IPCCC term. The web page is updated with the modifications, date of certification, and rating, in order to reflect the date of final approval.

1.3. AWG Web Portal Navigation: The IPCCC is organized in a hierarchal structure and is composed of Long Lists of nomenclature containing thousands of terms that are mapped to Short Lists of nomenclature that contain hundreds of terms. The navigation of the web site is based on the use of the IPCCC Short Lists. To navigate the web site, the user selects from drop-down menus to reach the areas of interest (Fig. 7.2). The user clicks on the image and code of interest to access the web page, where the codes, images, and explanatory texts are displayed (Figs. 7.3 and 7.4). The images and videos reflect a variety of modalities, including still images and videos of from cardiac morphologic specimens, echocardiograms, angio-cardiograms, computerized axial tomographic images, magnetic resonance

Fig. 7.3 This is an example of the first portion of a finished page with images, codes, and, when available, definitions and comments. The images for this page are shown in Fig. 7.4

images, and intra-operative images and videos. These still images and videos are stored and displayed using Web enabled standard formats such as JPEG (Joint Photographic Expert Group) for still images and Flash animation (Adobe Systems, San Jose, California, USA) for video clips.

1.4. Copyright Protection: An important feature of the AWG Web Portal is that the contributing author retains all copyrights to the images and has given permission for the portal visitor to view the images and to use them for not-for-profit, instructional, or educational purposes only. If the AWG Web Portal visitor wishes to use the images displayed for publications or for-profit-use, the visitor is free to contact the contributor of the image, who is identified and credited in each of the web pages posted, to obtain the necessary permissions.

2. **Lessons Learned**:

2.1. Senior Archivist: In spite of best intentions, unsolicited images with descriptions have been a minor portion of the images published in this 'virtual web-based encyclopedia' to date. This represents the most important lesson learned so far: the professional identification, photography and labeling of cardiac images is an 'absolute' necessity for a project of illustration of terms of classifications to be successful. Although not glamorous by current standards, cardiac morphologic specimens remain the

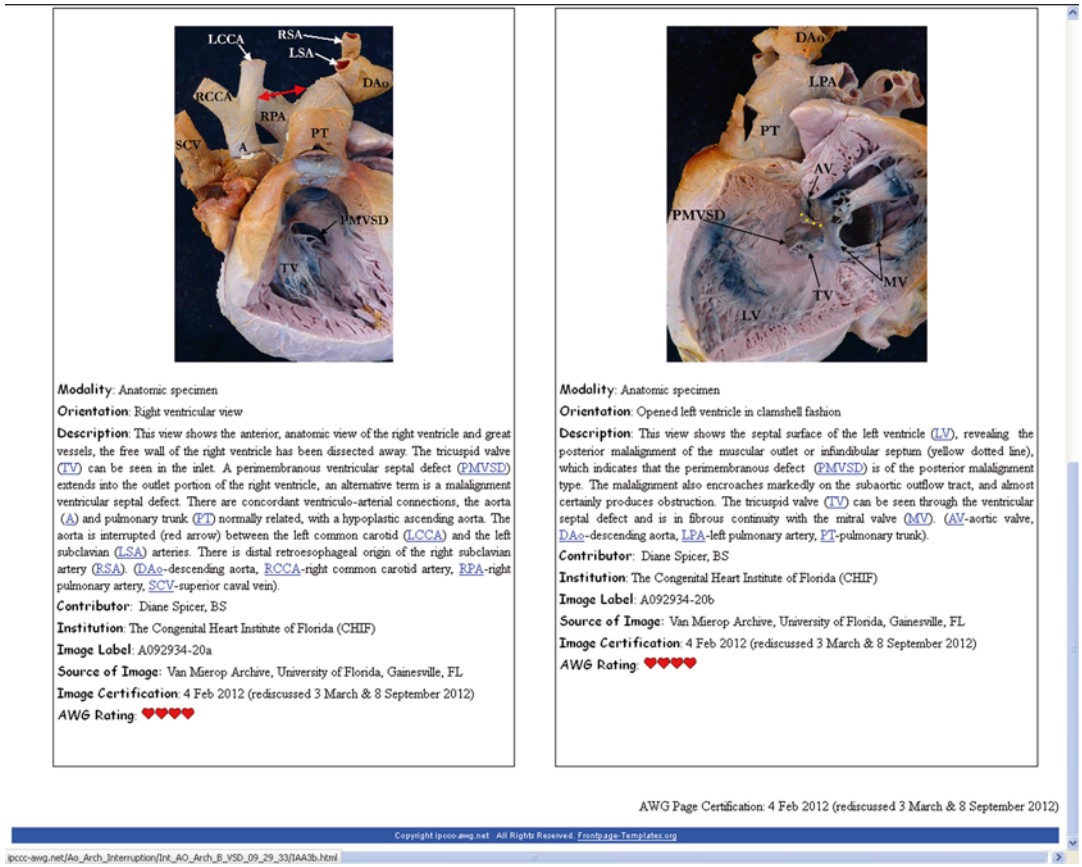

Fig. 7.4 This figure illustrates the images associated with the terms and definitions of the IPCCC shown in Fig. 7.2. Any of the images displayed, if selected, link to the full-resolution version. This allows for review of the image in greater detail or downloads for not-for-profit use. Please note the 'Certification' and 'AWG Rating' status listed for each image. The date of certification or review is added to the bottom of the page as well. This is done after the review process is completed by the AWG Editorial Board

cornerstone for the illustration of the definitions and terms of the IPCCC. In spite of increasing technological wonders, such as three dimensional reconstructions by magnetic resonance imaging (MRI) or echocardiography, a well photographed and labeled cardiac morphologic specimen continues to be an essential component of any 'encyclopedia' that wishes to illustrate terms and definitions of cardiac malformations. In a project such as the AWG Web Portal, it is of paramount importance to have a well educated and experienced Senior Archivist that is versed in the current embryologic and morphologic debates as well as the essential techniques of dissection and photography, and this experience is reflected in the quality of morphologic illustrations used in the AWG Web Portal.

2.2. Webmaster: It has been our experience that a technologically experienced member or 'Webmaster' must be identified and given the support necessary to create and maintain the process. This is a crucial component of any project that seeks to popularize the linkage of illustrations with terms using the Internet as the publishing medium. Technological familiarity is important but most be complemented with knowledge of congenital cardiac disease. This collaboration of this

Webmaster and the Senior Archivist is the key that helps in the creation of a web based, technological platform that reflects the current understanding of the meanings inherent in the terms and the illustration of the accompanying images.

2.3. Membership: Another crucial aspect in the organizational structure of a project that seeks to link images with list of terms is that the best available images that represent the phenotypes must not only be identified but also reviewed by a group of knowledgeable practitioners that are recognized within the field. The responsibility of the members is to insure that the images collected and linked are indeed the best examples of the terms and definitions listed in the posted pages. The international nature of such a project demands that the certifying members represent the global perspective of the modern standard of pediatric cardiac classification. Additionally, as in daily clinical practice, areas of particular expertise must be recognized and utilized in the process of identification, review, and certification. For example, with over 9,000 diagnostic terms in the EACTS-STS version of the IPCCC, and a similar number in the AEPC version of the IPCCC, it is imperative that an 'expert' for each of the coding systems be available for each review and certification session. In a similar vein, it is required that a cardiac morphologist participate in each review and certification session. We find that this participation significantly improves the accuracy and utility of each posted image and page. Additionally, at least one cardiac surgeon must participate in each session to complement the expertise of the morphologists and coding 'experts'. Finally, if the image that is being reviewed is that of a complex three dimensional reconstruction either by echocardiography or MRI, the participation of a member of the AWG that is familiar with these techniques is also required.

2.4. Funding: A project that seeks to illustrate terms with images using technology must be adequately funded in order to maintain its web presence. The domain name must be registered and maintained. The images and web pages must be hosted with enough capacity to both support traffic as well storage of images and text. The Senior Archivist must be funded in order to identify and photograph available morphologic specimens and help with the linkage of the diverse images identified and described. The telephony costs for the review and certification sessions must also be incorporated into the budget. The approach followed by the AWG for the AWG Web Portal is to allow full access with no cost incurred by the user or viewer. To date the AWG has been successful in identifying and obtaining funding for the project by grants and donations, in particular from The Children's Heart Foundation: http://www.childrensheartfoundation.org/. A research grant from The Children's Heart Foundation (Table 7.2) was critical to the development of the AWG Web Portal.

Summary

The effort to develop a web based platform to illustrate, with representative images and videos, the terms and definitions of The International Pediatric and Congenital Cardiac Code has been successfully implemented by the members of the Archiving Working Group (AWG) of The International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPCHD). The AWG maintains an active web presence known as the Archiving Working Group Web Portal. This 'virtual encyclopedia' combines the tools of classification incorporated into the lists of terms of the IPCCC, with the ancient tradition of using illustrations to help in the understanding of diseases of the heart. The goal of this chapter, 'Illustrating Terms in Lists of Nomenclature', guided by the modern

Table 7.2 The Children's Heart Foundation grant

Period of award: January 1, 2011 to December 31, 2012	
Title of project:	
Creation of a visual encyclopedia illustrating the terms and definitions of the International Paediatric and Congenital Cardiac Code, a system of nomenclature developed by The International Society for Nomenclature of Paediatric and Congenital Heart Disease	
Granting agency: the Children's Heart Foundation	
Amount of funding = $100,000 over 2 years	
Name of principal investigator: Jeffrey Phillip Jacobs, MD, FACS, FACC, FCCP	
Investigative team:	
Jeffrey Phillip Jacobs, MD, FACS, FACC, FCCP	Principal investigator
Jorge Manuel Giroud, MD, FACC	Co- principal investigator
Robert Anderson	Co-investigator
Marshall Lewis Jacobs, MD	Co-investigator
Hal Walters, MD	Co-investigator
Diane Spicer, BS	Senior Archivist
Tracey Griffith, LPN	Research nurse coordinator

understanding of the various forms of cardiac disease that affect neonates, infants, children and increasingly the young adult, has been effectively implemented by the Archiving Working Group of the International Society for Nomenclature of Paediatric and Congenital Heart Disease. Please visit us at http://www.ipccc-awg.net/.

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