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Newsletter from the Association for European Paediatric Cardiology

Further developments with the European Paediatric Cardiac Code

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WE LAST PROVIDED INFORMATION concerning the European Paediatric Cardiac Code in late 1999.[1] As we described at that time, the complete Code has short and long lists, which were presented first to the Council of the Association, and then to the General Assembly, at the Annual Meeting held in Sofia in October 1999. The Code received formal ratification on both occasions. Following this, the short list, mapped to the 9th and 10th revisions of the International Codes of Disease, and along with an introductory explanation, was published in the November issue of *Cardiology in the Young* for 1999.[2] As a second step, the complete short and long lists, together with their mapping to the International Codes, was published as a supplement to *Cardiology in the Young* in January 2000.[3] At the same time, we published the Code on the website of the Association (www.aepc.org), giving all interested individuals and groups the opportunity to download the entire system. At present, beside the original English text, there are versions in Dutch and German available on the website.

Thus, the Code has been in practical use since the beginning of 2000. We know that, up to June 2001, the Code has been downloaded 230 times from the website by members of the Association, or by other individuals and groups. Presently, the short list of the Code is used in Germany in connection with the official programme for assessment of quality. At the same time, the Swiss Society of Paediatric Cardiology is using the Code in a National survey. Both instances are examples of applications involving multiple centres.

The Code continues to be managed by a committee, which has now been enlarged by official representation from the European Association for Cardiac Thoracic Surgery, who nominated Tjark Ebels as their member, the Association for European Cardiovascular Pathology who are represented by Anton Becker, and the Working Group on Grown-up Congenital Heart Disease of the European Society of Cardiology represented by John Deanfield. The remaining members of the committee are unchanged, namely Bob Anderson, Otto Daniels, Martin Elliott, Rodney Franklin, Marc Gewillig, Renzo Ghisla, Otto Krogmann, Franco Stocker as Chairman, and Bert Ulmer.

All legal rights in connection with the complete Code are held within the Association which, by the same token, is alone responsible for any proposed changes in the Code. So as to ensure appropriate management, the Association has also drafted by-laws for its coding committee.

During 2001, the committee worked on the first up-dating of the Code. The final phase of this task is nearing completion, and the up-date will be published in *Cardiology in the Young* in the beginning of 2002. The up-date has incorporated suggested changes based on the experience of all the current users of the Code within the Association. It has also incorporated changes made necessary by the need also to map the short list to the comparable system of coding published by a consortium of American and European paediatric cardiac surgeons.[4] All the committee members, and the interested users, deserve our thanks for this up-dating, but a particular debt is owed to Rodney Franklin, who has worked over and above the call of duty in collating and validating the mapping between our short and long lists.

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In addition to this modification of our own Code, the committee has, since spring of 2000, been involved in the development of a second level of coding. This reflects the collaboration with the surgical team already discussed. Thus, in April 2000, the "Congenital Heart Surgery Nomenclature and Database Project", coordinated jointly by the Society of Thoracic Surgeons and the European Association for Cardiothoracic Surgery, was published as a supplement of the Annals of Thoracic Surgery.[4] As their Code is used by many surgeons across the world, it was logical to seek to cross-map their system with our own. Thus, a joint committee, consisting of representatives of the Association (Bob Anderson, Martin Elliott, Rodney Franklin, Franco Stocker and Bert Ulmer), along with representation from both the American and European surgeons, has worked for over a year to produce a meaningful mapping of the two short lists. Meetings to discuss progress were held in Frankfurt on October 6, 2000, at the Annual Meeting of the European Association for Cardiothoracic Surgery, and in Toronto on May 27, 2001, during the World Congress of Pediatric Cardiology and Cardiac Surgery. The joint committee has made excellent progress, and we anticipate that, shortly, it will also prove possible to publish the mapping of the two short Codes, together with the up-dating of our own Code. As indicated, this is anticipated for the beginning of 2002. Again, from our side of the collaborative venture, we are particularly thankful to Rodney Franklin, whose tremendous effort into the details of mapping has already been cited, and to Martin Elliott, who organized the two meetings. The complete mapping will facilitate greatly our ongoing collaboration with our surgeons, not only those who already use the European Paediatric Code,[3] but also those currently employing the Surgical Code.[4]

I can now announce, however, that we have moved to a third level of work. Clearly, it would be advantageous if, eventually, all cardiologists and all surgeons dealing with congenital cardiac disease used the same nomenclature and coding system. Such a happening would facilitate common understanding and team-work throughout the world. With this vision in mind, just prior to the World Congress of Pediatric Cardiology and Cardiac Surgery in Toronto, specifically on May 27, 2001, the first International Summit on Nomenclature for Congenital Heart Disease took place. At this meeting, it was unanimously agreed to create a Working Party to develop an International Nomenclature for Congenital Heart Disease. It was agreed that the Working Party would be made up of representatives of the different interested societies and groups. Our Association was amongst the first to nominate its official representatives. They are Bob Anderson, Rodney Franklin, Franco Stocker, and Bert Ulmer. The decision has already been taken to use the numerical component of our long list as the basis of the International Nomenclature, although the names used for the lesions themselves will clearly be the subject of extensive negotiation. A further important step has already been taken by our own Association, however, since at the Annual Meeting held in Stockholm on 1–5 September 2001, the Council and the General Assembly ratified the work in progress of the coding committee as described above.

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