



Association for European Paediatric Cardiology

Newsletter – December, 2009

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MUCH HAS HAPPENED DURING THE COURSE OF the year. The Association has elected its new President-Elect. The Association has also strengthened its co-operation with other organizations representing cardiologists in other continents. In the midst of the credit crunch, we are particularly pleased to report that the economical situation of the Association is well balanced, and that several teaching courses were organized during the year.

Business Meeting

Due to the World Congress being held in Cairns, Australia, the Association cancelled its Annual Meeting for 2009. The Business Meeting of the Association, therefore, was held on September 30 during the Congress of the European Cardiac Society in Barcelona. There were 50 members attending the meeting.

The Council had decided earlier that the annual meetings would not, in future, be cancelled in those years with a World Congress. One reason for this is that the Association is bound by its constitution to hold a business meeting in Europe every year, and the World Congress may be held in continents far from Europe. Business meetings organised as part of the meeting of the European Society of Cardiology have never attracted as many members as attend during our regular annual meetings.

Report from the President

Our president, André Bozio, is delighted to have been proposed as a member of the Council of Congenital Heart Diseases within the American College of Cardiology. He had been intimately involved in organizing the session devoted to the Fontan Circulation during the World Congress in Cairns. He was present not only to represent the Association during the congress, but also to participate together with the

Secretary-General and the Treasurer in the Constitutional Meeting of the Global Organization for Pediatric and Congenital Heart Diseases, held in conjunction with the Congress. The proposed constitution for the Organization will shortly be produced on the basis of these negotiations. Thanks to the active co-operation between the Association and sister organizations in other countries, he has been able to attend meetings held in Japan, Viet Nam, Egypt, Tunisia, Morocco, and Algeria. He chaired a joint meeting in Cairns between the Association and members of the Council of the Japanese Cardiac Society. On the basis of this meeting, it was agreed that a joint scientific session will be organized during the 44th Annual Meeting of the Association in Innsbruck, to be held in May of 2010.

Report from the Secretary-General

As we have emphasised in our previous Newsletters, teaching and training are amongst the major aims of the Association. To facilitate these activities, Council established, in 2009, the Educational Committee. The chairman of the committee is András Szatmári, with Tara Bharucha, Sandra Giusti, François Godard, and Joerg Stein serving currently as its members. Its major task is to harmonize the training in paediatric cardiology across Europe. This includes quality control of training, the organization, together with the working groups, of teaching courses, and in the future, the establishment of an European examination and site visits to training centers.

The Secretary-General had fruitful discussions with Christopher Hugo-Hamman, the President of the next World Congress, to be held in South-Africa in 2013. It was agreed that, as discussed above, the Association will not cancel its annual meeting to be held in 2013, and will be granted the presence of one member in the programme committee for the World Congress,

providing greater influence for the Association in the organisation of the programme than has been possible for the previous world congresses.

The Secretary-General is also well aware that web services need continuous updating and improvement. He is pleased to report in this regard that the Council is currently evaluates ways and means of re-organizing the web services.

Medical treatment of cardiac diseases in childhood, of course, remains an important issue within the European Union. In this respect, the Secretary-General is pleased to announce that the Association will co-operate with the so-called Teddy Project of the Union, this having the task of ensuring that medicines used for children are properly tested.

The Association has elected its new President-Elect

There were two official candidates in the ballot held over the summer, namely Ornella Milanese, from Padova in Italy, and Shak Qureshi from London, in the United Kingdom. A total of 353 eligible votes were returned, with Shak receiving 258 and Ornella 95 of the votes. On the basis of this result, the Business Meeting nominated Shak Qureshi as the new President-Elect, and he was delighted to accept the nomination.

Council thanks both the candidates for their candidacy, and for their interest in the work of the Association. We congratulate Shak Qureshi for his new position as the President-Elect. We all wish him the best of luck in the demanding task during these challenging times. Active voting is a strong demonstration of the democracy that is the strong point of our Association, the largest global democratic organisation currently existing in the field of congenital cardiac diseases.

Changes in the Council

Klaus Schmidt, from Dusseldorf, Germany, has stepped down as our treasurer. He has served in this role for 6 years, and the Secretary General and President, on behalf of all our members, thank him for his excellent work. He has been replaced by Joerg Stein, from Innsbruck, Austria, who will serve from 2009 until 2014. Konrad Brockmeier from Cologne, Germany, has also been elected as Councillor to serve from 2009 until 2012.

Tara Bharucha, from London in the United Kingdom, has stepped down as the councillor representing our junior members. To replace Tara, the junior members have elected Georgia Sarquella Brugada, from Barcelona, Spain, who will serve from 2009 through 2014. The Council is indebted to Tara for all her hard work in organizing teaching courses together with the working groups.

Future Annual Meetings will be organized as follows:

2010 Innsbruck
2011 Granada
2012 Istanbul
2013 London
2014 Helsinki

Report from the Treasurer:

The balance of the Association has been positive over the last six years. It was slightly negative in 2008, due to the fact that the surpluses of both the 2006 and 2007 Annual meetings were paid in 2007. In 2007, therefore, the positive balance of the Association was almost twice as high as during the previous years. The assets obtained during previous years have provided, and will provide, an important financial backbone for the Association during these economically challenging present and future years. In 2008, the balance was slightly negative, by 6,019 euros. As explained, this was in consequence of the lack of income from an annual meeting. The surplus of the Annual Meeting held in 2007 in Warsaw had already been transferred in 2007, while the surplus of the Annual Meeting for 2008, and held in Venice, was transferred only in August of 2009. The overall financial situation, nonetheless remains solid.

There is, however, an ongoing problem with payment of dues by the members. The improvement seen in 2006 and 2007 was sadly dissipated in 2008, and may well continue to be a problem for 2009. These annual fees provide the basis for our regular activities. In the absence of such fees, the Association is unable to arrange teaching courses, and to provide the members with the regular delivery of *Cardiology in the Young*. Thus, the Council urges those members who have not yet paid their membership fee to pay it immediately. This is easily achieved by using the on-line facility in the web page www.aepc.org. It is junior and ordinary members, along with those senior members who wish to receive the Journal, who are obliged to pay the annual fee. Senior members who do not wish to receive the Journal are not required to pay any annual subscription. Members whose subscription is more than two years in arrears, however, and who have received two requests for payment without response, will be considered to have resigned from the Association. Their names will be removed from the membership list, and they will no longer receive the journal. All those who are in arrears, therefore, are encouraged rapidly to pay their annual subscription.

Issues taken up by the members:

Emanuela Valsangiacomo Büchel asked how, in future, the Association intended financially to

support the activities of the working groups. Klaus Schmidt replied that, several years ago, the Association had made a one-time donation of 5000 euros to all the working groups. The Association was prepared, nonetheless, also to allocate funds to the working groups if the economical situation made this possible. In this respect, the Secretary-General pointed out that there was marked variability in the activity of the different working groups. It would be sensible, therefore, to support those working groups that are active, using their existing funds, for example, to organize teaching courses. The Educational Committee will also seek to clarify the various ways that financial support can be provided to the working groups.

The Secretary-General also asked the opinion of the audience regarding the opening of the membership of Association to nurses, as has now been done by the European Society of Cardiology. All but one of the attendees supported this notion. The Secretary-General, therefore, indicated that the Council will evaluate the Constitution, and possibly propose an amendment, or amendments, of the Constitution for consideration at the next Business Meeting.

Teaching courses

In addition to the Annual Meetings, the teaching courses are a corner stone of our educational activities. Our objective is to promote knowledge of the normal and abnormal heart and circulation during growth and development, and to ensure a high standard of professional practice in paediatric cardiology in Europe. With this in mind, the Association has created recommendations for training in Paediatric Cardiology, and strongly supports the teaching and training of younger colleagues over the course of their training. In support of this, different working groups of the Association have organized training courses for our junior members. During 2009, a course in echocardiography was held in Prague, and a basic teaching course on arrhythmias in Zurich, both being well attended. In addition, the second Teaching Course on Adult Congenital Heart Disease, organized together with the European Cardiac Society, took place in Antalya, in Turkey, on September 25 and 26.

News from the Working Groups:

Working Group for Cardiac Dysrhythmias and Electrophysiology

As a joint project, the Working Group of the Association, together with the working group for adults with congenital heart disease of the European Cardiac Society and the German Competence

Network for Congenital Heart Defects, have set up a prospective registry for children and adults with congenitally malformed hearts receiving implantable cardioverter defibrillators and undergoing cardiac resynchronization therapy. They have named it the Euripides device registry. The registry is web-based, and will cover data relating to the implantation and annual follow-up of these devices. A steering committee will manage the database, report to the Association and the European Cardiac Society, and answer research questions. Every person submitting data can apply for release of that data for research projects. A study nurse will ensure the completeness of the data, and provide updates. The working group thanks the German Competence Network for their very professional support. Initial financial support was received from various commercial companies. For more information, see also the website of the Association. All members of the Association are encouraged to participate in this important database. The manager of the database can be contacted at <euripides(at)kompetenznetz-ahf.de>. Those registering will be provided with a user name, password, and instructions for logging in to the registry, which started in July, 2007, and thus far has recruited 45 patients to the database.

A teaching course on arrhythmias was held in Zürich over the period April 24th and 25th, 2009. This course, our second, was again a great success, being attended by many fellows and young paediatric cardiologists. We thank Urs Bauersfeld and his team for their splendid organization, and the typical Swiss hospitality. In addition to state-of-the-art presentations, there were multiple interactive sessions on many topics in the field of paediatric arrhythmias. The third course is planned for April of 2011, and will be held in Leiden, the Netherlands.

The data of the retrospective European multicentric study on cardiac resynchronization therapy in children and adults with congenitally malformed hearts, coordinated by Jan Janousek, has recently been published in *Heart*. Another multicentric study has begun, headed again by Jan Janousek together with Tammo Delhaas, and looking at the detrimental effects of different sites of pacing in patients with isolated atrioventricular block. The working group has also planned a multicentric study on exercise-induced catecholaminergic polymorphic ventricular tachycardia in children.

Working Group on Cardiovascular Morphology

As morphologists and pathologists, we participated actively in the Congress of the European Cardiac Society held in Barcelona, Spain, with the morphology session focusing on congenitally corrected

transposition. As is usually the case, the session was very well attended. It was chaired by Yen Ho and André Bozio, with Annalisa Angelini presenting the morphological material.

European morphologists made notable contributions to the recent World Congress held in Cairns, Australia. Morphological demonstrations were arranged to match symposiums organized within the overall programme of the meeting. The specimens, obtained from the archive of Westmead Children's Hospital in Sydney, were kindly provided for live demonstrations by Richard Hawker. Richard, together with Bob Anderson, showed to a packed hall the anatomic lesions that nowadays are converted to the Fontan circulation. Bob concentrated on the morphological variability, and Richard emphasised the features of surgical and postoperative significance. Andrew Cook showed the essential anatomic features of the hypoplastic left heart syndrome to an equally interested and fascinated audience, illustrating the findings of both diagnostic and surgical significance. Dick Van Praagh, together with Louise Calder, showed the essential features of congenitally corrected transposition, and Amy Juraszek illustrated the features of tetralogy of Fallot with pulmonary atresia. Bob Anderson was also privileged to be able to present the landmark lecture on cardiac morphology, in which he emphasised the recent renaissance in cardiac embryology, a topic also presented in a featured session with great elegance by Adri Gittenberger-de Groot. Bob Anderson also delivered the second Stella Van Praagh lecture, this being the inaugural presentation in the symposium organised by the World Society of Pediatric Cardiac Surgery. This talk was devoted to the anatomic features of atrioventricular septal defect.

Interventional Working Group:

The recommendations for training in interventional cardiology have been finalized in 2008 by Maarten Witsenburg and his colleagues, and are currently submitted for approval prior to their publication.

A new teaching course will be organised on 19 and 20th March, 2010. We received two offers for hosting the meeting, one from Lisbon headed by Rui Anjos, and the other from Barcelona, with Fredy Prada in charge. During the meeting held in July in Frankfurt, the council chose Lisbon to host the course. The course will take up to 35 attendees and will be provided at low cost. Presentations will be standardised on the basis of a draft provided to the speakers, and will be used to create, on our website, a new cook book for interventions. It is also hoped to involve some junior fellows in the presentation of difficult cases.

The working group discussed several times establishing some kind of quality- control in the

same way that surgeons have achieved with the Aristotle score. Grazyna Brzezinska, therefore, contacted the Congenital Database Coordinator of the European Association for Congenital Thoracic Surgeons, but the costs involved seemed too high for our working group. David Nykanen, in the United States of America, nonetheless, is currently establishing a web-based database for complications. We will be looking at the possibility and conditions to join this programme.

The working group also discussed improving its website. The new ideas are:

- renovating the cook book as mentioned above
- introducing active consultation and exchange of opinions
- giving the possibility of preparing some lectures based on information carried on our website
- building new registries, for example for aortic coarctation of aorta or persistent patency of the arterial duct

The working group currently has some money available, which could be used for this purpose.

Many members of the Association are involved in humanitarian aid in developing countries. Lee Benson, from Toronto, suggested that the interventional working group should consider playing a role in organizing the distribution of materials required for catheterization in developing countries. We are exploring potential means of achieving this goal.

Psychosocial working group:

Hanna Milczarek kindly agreed to host the next meeting in Poland, which took place over the second week of October in Lodz, Poland. It was a multi-disciplinary meeting, with participation of professionals and parents. The topics for discussion included the effects of prenatal diagnosis, genetic counselling, possible stem cell therapies, pregnancy for the woman treated for congenital heart disease, and the psychosocial impact of congenital cardiac disease in adolescence.

So as to encourage research in the area of Psychosocial Care in Congenital Cardiac Disease, the group has agreed to award a prize of 1000 euros to the best research in this area presented by a young investigator at the biannual meeting of the Working Group. A further sum of 1000 euros will be awarded to the winning project team when the research is published in a peer reviewed journal.

Parental support groups have always had an important input into the work of the group. European self-help-groups for congenital cardiac disease have now united themselves under the umbrella of European Congenital Heart Disease Organisation, with a website at www.ECDO.org.

Its aims are:

- to liaise with other European networks
- to provide up-to-date information about congenital cardiac disease to all European patients and their families
- to lobby for European standards on medical and psychosocial care of our patients
- to ensure the safety of drugs for all European patients with congenital cardiac disease
- to improve the circumstances of grown up patients with congenital cardiac disease in Europe
- to provide information about research studies within Europe and share results and experiences

The group held their fourth meeting on the 19th of June, 2009, in Barcelona. The Psychosocial Working Group will continue to collaborate with, and support the work of, the European Congenital Heart Disease Organisation.

Fetal Cardiology working group

The dead line for submission of new cases to the European multicentric study on isolated atrioventricular block in the fetus was extended until the end of 2008, upon request by members of the fetal working group. Out of a total of 179 patients from 27 centres, selected patients with incomplete atrioventricular block at time of diagnosis were revised again by members of the study group, 4 patients being excluded, either due to erroneous diagnosis or simply because there were no videotape of satisfactory quality. Preliminary results are ready, but will need a second revision by a statistician. A first draft was circulated in October.

The working group was asked by Rodica Toganel, from Romania, to support their first fetal cardiology training programme at a course held in Tirgy, Mures in October, 2008. Joanna Dangel gave several talks to the 60 participating obstetricians and paediatric cardiologists. The meeting was very well received, and was repeated in the fall of 2009.

The council also discussed the possibility of arranging a course at low cost for junior paediatric cardiologists, possibly to be held in Warsaw in the autumn of 2010. Reduced registration fees are already offered to trainees for courses arranged in London. The council reviewed the free online teaching course in fetal cardiology produced by Lindsey Allan, which is available at www.fetalmedicine.com, and will advertise and recommend it on the web page of the Association.

Imaging working group

Thanks to the commitment of Luc Mertens, John Simpson, and Folkert Meijboom, with the endorsement of our working group, the 4th European

Echocardiography Course on Congenital Heart Disease was held in Rotterdam from September 30 through October 3.

Our group was also able to organize a congenital programme as part of the EuroEcho meeting, held in Lyon last December 2008. We are now involved in the organization of the congenital programme for the meeting of 2009, which will take place in Madrid in December.

An accreditation examination in echocardiography in congenital cardiac disease was held in Lyon in December, 2009. The examination was very successful, with numerous participants and good scores. The feedback from the candidates was very encouraging and the standard has certainly been set. The next accreditation examination will be held during the Annual Meeting of the Association in Innsbruck, in May of 2010. This is another important step towards higher quality in paediatric echocardiography in Europe.

We organized one session on congenital cardiac malformations at the 7th meeting of the EuroCMR Working Group, which took place in Athens over the period May 21 through 23.

An important activity has been completed, as the survey on imaging modalities in Europe, conceived by Luc Mertens during his secretariat, has been finished by our President, Emanuela Valsangiacomo. We sent a questionnaire to all the European tertiary centers concerning the imaging modalities adopted during the diagnostic process of the most important congenital cardiac defects. About 70 centres replied, and the data is now being processed. The results of the survey will be presented during the next annual meeting of the Association in Innsbruck.

Task Force for Grown-ups with Congenital Heart Defects

Based on the tight cooperation with Congenital Working Group 22 of the European Cardiac Society, congenital cardiology was represented in Barcelona, during the Congress of the European Cardiac Society, by several pre-arranged symposiums and abstract sessions.

As already mentioned, a joint course between the Association and the European Society of Cardiology was organized for the second time in Antalya, Turkey, on 25 and 26 September, 2009. A similar joint meeting is planned to be held in Lund, Sweden, on 22 and 23 October, 2010. The working group will also participate in the Annual Meeting of the Association to be held next year in Innsbruck.

Annual Meeting in Innsbruck:

Please mark now in your calendar the dates for the Annual Meeting to be held in 2010.

The dates are 27 through 29 of May, and the meeting will be held in Innsbruck, Austria. The scientific meeting is preceded by an Update Course on Wednesday, May 26, 2010. Please visit the official web page of the Annual Meeting at <http://www.aepc2010.at/>. There is also a link to this page on the home page of the Association. We warmly invite all of you to join us next spring in Innsbruck.

In closing our Newsletters for 2009, we hope all our readers will have a peaceful and relaxing Holiday Season, and we conclude by wishing you a merry Christmas, and a happy and prosperous 2010.

Eero Jokinen
Secretary-General

André Bozio
President