

Annual Report 2008-2009

Part 1: Identification

Working Group on: **GROWN-UP CONGENITAL HEART DISEASE**

Nucleus composition (name):

Chairperson: **Folkert Meijboom**
Vice-chairperson: **Pedro Trigo Trindade**
Past chairperson: **Helmut Baumgartner**
Treasurer: **Öztekin Oto**
Secretary: **Andras Szatmari**
Web editor: **Antonia Pijuan-Domenech**
Nucleus Members: **Laurence Iserin, Rafael Hirsch, John Deanfield, Johan Holm, Harald Kaemmerer**

Part 2: Turn-Over of the WG during the year

Election:

Chair/Organisation committee: This year there were no changes – next year, in 2010, 3 new nucleus members will have to be elected, since John Deanfield, Rafael Hirsch and Harald Kaemmerer will leave the nucleus. The last two will be asked to stay as ex-officio members because of their involvement in the WG teaching courses.

Part 3: Activities of the WG during the year

- ▶ **WG Annual Meeting(s):** In Barcelona during the ESC congress: we had a well attended business meeting on Monday 31 August. We had an extra nucleus meeting in Utrecht on 27 March 2009 and the regular nucleus meeting in Barcelona, on Saturday 29 August.
- ▶ **Endorsed Meeting(s):**
 - First ESC teaching course on Grown-up congenital heart disease in Antalya, 28 and 29 November 2008, organized by WG 22.
 - Third European Echocardiography course on congenital heart disease, in Prague, 1-4 October, joined effort with EAE, AEPC and WG 22.
 - 6th advanced symposium on congenital heart disease in the adult, Thessaloniki 26 and 27 September, organized by prof Gatzoulis, endorsed by WG 22.
- ▶ **Education programme(s) – Training, Courses & Grants**
 - No current programmes.
- ▶ **Publications / Guidelines / Scientific Papers**
 - **Recommendations for Cardiovascular Magnetic resonance in adults with congenital heart disease.** By Philip Kilner (London), Tal Geva (Boston), Harald Kaemmerer (Munich; nucleus member), Pedro Trigo Trindade (Zurich, nucleus member), Juerg Schwitler (Geneva), Gary Webb (honorary member of the WG). Submitted to the *Eur Heart Journal*
 - WG officially affiliated to a journal? – no

- Number of WG Publications - none
- Position Papers / Consensus Documents – none
- **Participation to guidelines - writing / reviewing**
 - **The guidelines on Grown-up Congenital Heart Disease** are under revision now. The writing group is chaired by Prof Baumgartner from Münster, Germany. Three meetings have taken place so far and the guidelines are expected to be ready in Spring 2010.
- ▶ **Proposals for pre-arranged sessions at the ESC main congress and/or ESC Sub-specialty meetings**
 - ▶ A total of 3 pre-arranged sessions were proposed at the CPC meeting in November – the maximum number of sessions that is allotted to small WGs – but since we had shared proposals with the WG on Pulmonary Hypertension and the WG on Valvular Heart Disease, we had a total of 5 sessions. On top of this, the ISACHD was allowed an extra session on Congenital Heart Disease and the AEPC had an extra session. Both the number of sessions we had at the ESC and the quality of the sessions was the best in years. The attendance was also exceptional (for our standards): rooms for 250 people were at least 75% full for all sessions. For 2010 a similar approach is adopted. On top of the regular session, there is an effort to get a Focus session on congenital heart disease on the programme for 2010.
- ▶ **Task Force(s):**
 - A task force is prepared now on prevalence of GUCH in Europe; details remain to be filled in. A final proposal will follow in fall 2009.
- ▶ **Registry / Survey:** 2 registries are running
 - **Pregnancy registry**, since December 2007, with > 600 patients in Europe included, lead by Jorg Stein, Jolien Roos-Hesselink and Roger Hall. The inclusion period is extended and several North American centres consider participation as well.
 - **Euripides: registration of ICD implants and CRT in Europe.** So far predominantly a German effort, with 31 included patients and only 1 patient included outside Germany. This survey is lead by Kolb, Janousek, Bauersfeld, Pflaumer and Hebe.
- ▶ **Other:**
 - **Accreditation:**
 - The accreditation examination for echocardiography for congenital heart disease has been held during EuroEcho in Lyon in December 2008 for the third time. There were 29 participants; the number is small but gradually rising. The fourth edition is planned for EuroEcho in Madrid in December 2009.
 - **Membership:** the WG now has **231 members**. In the coming year we will update the list and allocate as many members with correct mail addresses and affiliations as we can.

- **Web:** there is a good web page for our WG with an active web editor, Antonia Pijan Domenech from Barcelona, Spain. The help from Céline Serio from the Heart House is much appreciated. During our nucleus meeting in Barcelona we learned that in terms of number of hits, our WG web-page was ranked 7th from all WG webpages.

Part 4:

▶ **Future projects**

- Apart from the basic teaching course for congenital heart disease started in 2008, of which a second will take place in September 2009, the first advanced course on adult congenital heart disease organized by the WG will take place in London, 15 and 16 April 2010. The idea is to merge the basic teaching and the advanced course in one meeting, that initially will take place every other year in a different place in Europe. The ultimate goal is to come to an annual "EuroCongenital" meeting, as a joint meeting with the AEPC and the EACTS (congenital cardiac surgeons society).
- For 2010, a Task Force is planned to come to a position paper on the prevalence of adult congenital heart disease in Europe. Funding (€10.000) from the ESC will be requested.

▶ **Finances:**

- Prepare your balance sheet:
- List your Income:
 - There is no income apart from the support by the ESC. The annual €10,000 for the extra nucleus meetings in 2008 and 2009 have been asked for. The financial administration, with integration of the amount of money that was on the WG account before the annual €10,000 rule was introduced, with the administration of the finances of the extra nucleus meetings in Münster in 2008 and in Utrecht in 2009, is presented as attachment.
- List your main expenses:
 - The main expenses are the extra nucleus meeting (see financial overview). These are annual costs for a regular event.
 - An incidental cost is the €1,498,- for the social event in Barcelona during the ESC congress. There is a tradition of having a social event for the WG at every ESC congress. The main purpose is that members can get acquainted to each other; this will promote cooperation and facilitate multi-centre research. In previous years it had always been possible to find a sponsor for the social event, but not this year. We assume that is was mainly due to the economical situation, combined with stricter rules for the pharmaceutical industry. The nucleus had decided that it was an essential activity of our WG members and decided to pay for this social event from the WG account at the ESC. It was paid for by the chairman of the WG and the listed €1,498,- concerns the refund of this amount to the chairman, Folkert Meijboom.
 - A second incidental cost is €5,000,- as backup money for the 2nd basic teaching course on Adult Congenital Heart Disease in Antalya, Turkey on 25 and 26 September 2009. The co-organizing organizations, AEPC and

German Kompetenz Network and WG 22 all promised €5,000,- as backup money in case of financial shortages. There are substantial shortages, since despite a very good and well attended first course in 2008, a well advertised course in 2009 with a good program, a nice venue and a beautiful website, the number of registered participants for the 2009 edition was 0 (zero) until 3 weeks before the course.