

Annual Report 2006-2007

Working Group on Grown-up Congenital Heart Disease

Nucleus:

Chairperson: H. Baumgartner, Vienna (AT)

Vice-chairperson: F. Meijboom, Rotterdam (NL)

Past chairperson: H. Kaemmerer, Munich (DE)

Treasurer: Oe. Oto, Izmir (TR)

Secretary: P. Trigo Trindade, Zurich (CH)

Web editor: to be announced

Nucleus Members: J. Popelova (CZ), JE. Deanfield (GB), R. Hirsch (IL), U. Thielen (SE), A. Szatmari = representative of AEPC (HU)

ORDINARY MEMBERS: 211

Specific Committees: see task forces and projects

VOTE:

(Elections during 2007 Ø) Last elections were in 2006, next elections will therefore be in 2008

Activities

WG Annual Meeting(s):

The WG has no meeting on its own but plays an important role within **EuroEcho** with a full day teaching course, several symposia and a DICE session

Endorsed and Co-organized Meeting(s):

- **Meeting 1:**
EUROECHO 10, Prague, Dec. 2006
(see above)
- **Meeting 2:**
Annual AEPC meeting, Warsaw, May 2007
(WG organized a one day teaching course on GUCH)
- **Meeting 3:**
Echocardiography in congenital heart disease, Leuven, 2006
(co-organized by WG vice-chairman)
- **Meeting 4:**
D-A-CH Symposium on Grown-up Congenital Heart Disease, Vienna, 2007
(organized by WG chairman)
- **Meeting 5:**
Structural and congenital interventions, Frankfurt, 2007
(endorsed)

Education programme(s)

Trainings: None

Courses: Teaching courses within EuroEcho and AEPC congresses (see above)

Fellowship Program / Grants: None

Publications / Guidelines / Scientific Papers

- **WG is not officially affiliated to a journal**

- **WG Publications (e.g.: Reviews, Original Studies)**

Based on the Euro Heart Survey Grown-up Congenital Heart Disease the following papers could be published or are in preparation:

The spectrum of adult congenital heart disease in Europe. *Eur Heart J* 2005 (Engelfriet et al)

Adherence to guidelines. *Eur Heart J* 2006 (Engelfriet et al)

GUCH- The organisation of care. *Eur Heart J* 2006 (Moons et al)

The distal aorta in Marfan syndrome. *Heart* 2006 (Engelfriet et al)

Radiation exposure in ACHD patients. *Int J Cardiol* 2006 (Hoffmann et al)

Pulmonary arterial hypertension in septal defects. *Heart* 2006 (Engelfriet et al)

Epidemiology of ASD in adults. *Int J Cardiol* 2007 (Engelfriet/Meijboom et al)

Smoking and mortality in ACHD. *Int J Cardiol* 2007 (Engelfriet et al)

Gender in ACHD. *Int J Cardiol* 2007 (Engelfriet et al)

Fontan patients in the EHS. *In preparation* (Thilén et al)

LV dysfunction in TOF patients. *In prep.* (Bouzas/Gatzoulis et al)

Pregnancy and heart function in CHD. *In preparation* (Budts et al)

- **Position Papers / Consensus Documents**

WG plans to write "**Recommendations for the assessment of congenital heart disease by MRI**" together with the MRI WG (chair: P. Trigo Trindade, Zurich, Switzerland)

- **Participation to guidelines - writing / reviewing**

WG chairman was member of the writing group for "**Practice Guidelines on the Management of Valvular Heart Disease**" (*Eur H J* 2007)

Practice Guidelines on the management of Adult Congenital Heart Disease were published in 2003. The WG applied this year for a revision which was accepted. Process will start in 2008

Sessions at the ESC main congress (Vienna 2007)

- SYMPOSIA

Chronic right heart failure (Mo 8:30)
Valvular problems in ACHD (Mo 11:00)
Arrhythmias in ACHD (Mo 16:30)
Heart failure in ACHD (Tue 8:30)

- FOCUS SESSIONS

Important problems in ACHD (Mo 14:00)
PFO: open or close (Tue 11:00)

- WORK SHOPS

Surgical anatomy in CHD (Mo 15:45)
Atrial septal interventions in adults (Tue 12:45)

- Featured Research

State of the art: Interventional therapy in CHD (We)

- **Abstracts** (32): Oral Session (Su 16:30) Poster Session (Su morning)

Task Force(s)

TF "ICD and CRT Devices in Pediatrics and Adults with Congenital Heart Disease"

Chair: U. Bauersfeld, Zurich (Switzerland)
TF members: Joachim Hebe, Bremen (Germany)
J. Janousek, Leipzig (Germany)
Ch. Kolb, Munich (Germany)
A. Pflaumer, Munich (Germany)
G. Stix, Vienna (Austria)
U. Bauersfeld, Zurich (Switzerland)
Topic: To establish a European registry

TF "Pregnancy in Adult Congenital Heart Disease and Valvular Heart Disease"

Chair: J. Stein, Innsbruck (Austria)
Co-chair: Jolien Roos-Hesselink (NL)
Topic: To establish a European registry

TF "European Centers of Adult Congenital Heart Disease"

Chair: H. Kaemmerer, Munich (DE)
Co-chair: H. Baumgartner, Vienna (AT)
Topic: To establish a European registry

Registry / Survey

Euro Heart Survey on Grown-up Congenital Heart Disease

Chair: B. Mulder, Amsterdam, Netherlands (finished)

EURIPIDES: European Registry for ICD and CRT Devices in Pediatrics and Adults with Congenital Heart Disease

Chair: U. Bauersfeld, Zurich (Switzerland); Committee members: Joachim Hebe, Bremen (Germany) J. Janousek, Leipzig (Germany) Ch. Kolb, Munich (Germany) A. Pflaumer, Munich (Germany) G. Stix, Vienna (Austria)

Prospective, web based ICD, ICD-CRT and CRT follow-up registry

The registry is now open for data entry

Internet access via www.escardio.org/GUCH or www.kompetenznetz-ahf.de

Email: euripides@kompetenznetz-ahf.de

European Registry on Pregnancy in Adult Congenital Heart Disease and Valvular Heart Disease

Chair: J. Stein, Innsbruck (Austria), Co-chair: Jolien Roos-Hesselink (NL)

The last preparations will be finished by the end of the year. The registry will open January 1st, 2008

Registry of European Centers of Adult Congenital Heart Disease

Chair: H. Kaemmerer, Munich (DE)

Co-chair: H. Baumgartner, Vienna (AT)

The registry is currently up-dated by Ph. Moons, Leuven (BE)

Other:

- **Accreditation:**

- **Accreditation in Congenital Heart Disease Echocardiography**

- Chair: F. Meijboom, Rotterdam (NL) and L. Mertens, Leuven (BE)

- The first exam took place at EuroEcho 2006 (Prague) and the next exam is planned for EuroEcho 2007 (Lisbon)

- **Membership:**

- Chair: WG chairman / organisation committee in charge of reviewing and evaluating application forms: Nucleus

- **Web:**

- Chair / organisation committee in charge of web updates and e-communication: chairman and vice-chairman

Ongoing and Future projects:

(main responsible person)

- **Promotion of registries**
 - Euripides** (U. Bauersfeld, Zurich, CH)
 - Pregnancy** (J. Stein, Innsbruck, AT)
 - European Centers** (Ph. Moons, Leuven, BE)
 - **Writing Committee: Recommendations for the use of MRI in ACHD**
(P. Trigo Trindade, Zurich, CH)
 - **Revision of Guidelines on the Management of Adult Congenital Heart Disease**
(H. Baumgartner, Vienna, AT, F. Meijboom, Rotterdam, NL and J. Deanfield, London, GB)
 - **Preparation for Accreditation Subspecialty Adult Congenital Heart Disease /Core Curriculum**
(F. Meijboom, Rotterdam, NL and H. Baumgartner, Vienna, AT)
 - **AEPC and ISACCD relations**
(H. Baumgartner, Vienna, AT, A.Szatmari, Budapest and F. Meijboom, Rotterdam, NL)
 - **Teaching Course on Adult Congenital Heart Disease 2008**
European Heart House or extramural
(H. Kaemmerer, Munich, DE; J. Deanfield, London, GB; P. Trigo Trindade, Zurich, CH)
 - **Preparation of a European meeting on Congenital Heart Disease – “Euro Congenital 2009”**
(F. Meijboom, Rotterdam, NL and H. Baumgartner, Vienna, AT)
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Finances:

Balance on 29/08/07: € 7.344,15

INCOME:

Currently no income besides ESC support

Income from ESC entities:

- Actual Ø
- Forecast for next fiscal year: Re-imburement for nucleus meeting

Industry sponsorship:

- Actual Ø
- Forecast for next fiscal year?

MAIN EXPENSES:

Please specify amount & purpose.

- Actual Ø
- Forecast for next fiscal year: Secretarial help
Nucleus meeting in Muenster January 2008: € 10.000.-

