

## Working Group on: Grown-up Congenital Heart Disease (GUCH)

Annual Report 2007-2008

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### The Nucleus composition for 2008-10:

**Chairperson:** Folkert Meijboom (NL)

**Vice-chairperson:** Pedro Trigo Trindade (CH)

**Past chairperson:** Helmut Baumgartner (DE)

**Treasurer:** Öztekin Oto (TR)

**Secretary:** Andras Szatmari (HU)

**(Web editor:** Antonia Pijuan-Domenech (ES) no nucleus member)

**Nucleus Members:**

Harald Kaemmerer (DE)

John Deanfield (GB)

Raphael Hirsch (IL)

Johan Holm (SE)

Laurence Iserin (FR)

Specific Committees: see below (TF etc)

### Elections during 2008

Chair / organisation committee: Helmut Baumgartner

Date: May 2008

Place: internet

Position(s) to be occupied: 2 nucleus members

Names of Candidates: Massimo Chessa  
Johan Holm  
Laurence Iserin  
Antonia Pijuan-Domenech

Number of voting delegates (WG members): 222

Number of registered participants (votes): 77

Results:	Massimo Chessa	41.6%
	Johan Holm	55.8%
	Laurence Iserin	58.4%
	Antonia Pijuan-Domenech	44.2%

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## Activities

### WG Annual Meeting(s):

The Working Group had until this year no meeting on its own but has played and continued to play an important role within **EuroEcho** with a full day teaching course, several symposia and a DICE session.

In 2008 the first, and hopefully from now on annual meeting will take place:  
**Adult Congenital Cardiac Disease: what you always wanted to know, Antalya, Nov. 28/29 2008**

### Endorsed Meeting(s):

- Meeting 1:  
Adult Congenital Heart Disease Symposium, Toronto, June 2008
- Meeting 2:  
Echocardiography in congenital heart disease, Prague, 2008
- Meeting 3:  
Structural and congenital interventions, Frankfurt, 2008

### Education programme(s)

- Full day **teaching courses** within EuroEcho 2007 and 2008
- **ESC/AEPC Teaching course in grown-up congenital heart disease: Adult Congenital Cardiac Disease: what you always wanted to know**  
Antalya, Nov. 28/29 2008

### Publications / Guidelines / Scientific Papers

- **Is your WG officially affiliated to a journal? Y/N**
- **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:
  1. Epidemiology of ASD in adults. *Int J Cardiol* 2007 (Engelfriet/Meijboom et al)
  2. Smoking and mortality in ACHD. *Int J Cardiol* 2007 (Engelfriet et al)
  3. Gender in ACHD. *Int J Cardiol* 2007 (Engelfriet et al)
  4. Fontan patients in the EHS. *In preparation* (Thilén et al)
  5. LV dysfunction in TOF patients. *In prep.* (Bouzas/Gatzoulis et al)
  6. Pregnancy and heart function in CHD. *In preparation* (Budts et al)

- **Position Papers / Consensus Documents**

**Recommendations for the use of MRI in adult congenital heart disease** (joint project with MRI WG) Ph. Kilner et al (in final preparation)

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

**ESC Guidelines on the management of valvular heart disease**

(H. Baumgartner, task force member) finished and published 2007

**ESC Guidelines on the management of grown up congenital heart disease**

(chairman: H. Baumgartner; started ESC congresses 2008)

**Proposals for pre-arranged sessions at the ESC main congress and/or ESC Sub-specialty meetings**

**Accepted Sessions at ESC 2008, Munich:**

Stroke and migraine: a cardiologist's headache

Application of new imaging techniques in congenital heart disease

Pulmonary hypertension in adult congenital heart disease

How to diagnose and manage rare and unusual cardiomyopathies  
(joint session with Myocardial and Pericardial Disease)

Longterm risk of congenital heart disease (features research)

Risks and benefits of catheter interventions in congenital heart disease (abstracts)

Challenging issues in adult congenital heart disease (abstracts)

Imaging an intervention in congenital heart disease (abstracts)

Adult congenital heart disease: Clinical Issues (abstract)

**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)

**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, Muenster (DE)  
Topic: To establish a European registry

**TF “Accreditation in Adult Congenital Heart Disease”**

Chair: F. Meijboom (NL)  
Co-chair: H. Baumgartner (DE), H. Kaemmerer (DE)

**Registry / Survey**

**Euro Heart Survey on Grown-up Congenital Heart Disease**

Chair: B. Mulder, Amsterdam, Netherlands (analysis still going on)

**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  
Internet access via [www.escardio.org/GUCH](http://www.escardio.org/GUCH) or [www.kompetenznetz-ahf.de](http://www.kompetenznetz-ahf.de)  
Email: [euripides@kompetenznetz-ahf.de](mailto: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)  
Internet access via ESC website and WG website

**Registry of European Centers of Adult Congenital Heart Disease**

Chair: H. Kaemmerer, Munich (DE)  
Co-chair: H. Baumgartner, Muenster (DE)  
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)  
Since 2006 every year at EuroEcho
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## Future and ongoing projects

- **Promotion of registries**  
**Euripides** (U. Bauersfeld, Zurich, CH)  
**Pregnancy** (J. Stein, Innsbruck, AT)
- **Recommendations for the use of MRI in ACHD** (P.Trigo Trindade, Zurich, CH)
- **Revision of Guidelines on the Management of Adult Congenital Heart Disease** (Chairman: H. Baumgartner , DE)
- **Preparation for Accreditation Subspecialty Adult Congenital Heart Disease /Core Curriculum**  
(F. Meijboom, Nijmegen, NL and H. Baumgartner, Muenster, DE)
- **AEPC and ISACHD relations**  
(H. Baumgartner, Muenster, DE, A.Szatmari, Budapest and F. Meijboom, Nijmegen, NL)
- **Teaching Course on Adult Congenital Heart Disease 2008**  
(planned to be continued on a regular basis)  
(H. Kaemmerer, Munich, DE; P. Trigo Trindade, Öztekin Oto, TR;  
Zurich, CH; H. Baumgartner, Muenster, DE; A. Szatmari, Budapest, HU)
- **Preparation of a European meeting on Congenital Heart Disease – “Euro Congenital”**  
(F. Meijboom, Nijmegen, NL and J. Deanfield, London, GB)

## Finances

Balance sheet: (30/6/2008): 13130,02 Euros

**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:**

- Actual Ø
- Forecast for next fiscal year: Secretarial help  
Nucleus meeting in Nijmegen 2009: € 10.000