



# ANNUAL REPORT

## Identification

**Working Group on: GUCH**

### Nucleus Composition

(Precise name, surname and country)

Chairperson	Johan Holm ....	
Vice-chairperson	Andreas Eicken	
Past Chairperson	Pedro Trigo Trindade	
Treasurer	Massimo Chessa	
Secretary	Werner Budts.	
Nucleus Members .....		1 Jolien Roos Hesselink 2-Markus Schwerzmann 3-Jörg Ingolf Stein 4-Fiona Walker 5-

Specific Committees Ex officio members Helmut Baumgartner, Folkert Meijboom, Andras Szatmári.

### Elections: in 2014

Chair / Organisation committee .....	
Date .....	
Place .....	
Position(s) to be occupied 4 .....	
Names of Candidates .....	
Number of voting delegates (WG members) .....	
Number of registered participants (votes) .....	
Results .....	

Massimo Chessa, Pedro Trindage, Fiona Walker and Jörg Stein will step down. Ex officio members Helmut Baumgartner, Folkert Meijboom and Andras Szatmári will step down.

**New election:** Elected vice chairman is Werner Budts. New elected nucleus members 2014 are **Gerhard Diller**, Germany, **Lorna Swan**, UK, **Alessandro Giamberti**, Italy and **Julie de Backer**, Belgium

Ex officio member for 2015 annual meeting is **Fiona Walker**, ex officio member for the GUCH WG book series and AEPC representative is **Massimo Chessa**.

## Activities of the Working Group during the 2 past years

### Meetings

(For each meeting, please precise titles, dates, places, number of participants):

WG Annual Meeting(s): Fifth European meeting on adult congenital heart disease, Amsterdam 10-11 April 2014  
 Fourth annual meeting Milan 2013  
 Endorsed Meeting(s): 8<sup>th</sup> European Echocardiography course, Bologna October 23-26  
 Education programme(s) – Training, Courses & Grants:

### Papers & Guidelines

(For papers and publications, please precise titles, authors and journal/issue where the paper is published)

Publications & Scientific Papers submitted by the WG, not by individuals

#### **Physical activity in adolescents and adults with Congenital heart defects: individualized exercise prescription**

Werner Budts<sup>1,2\*</sup>, Mats Boerjesson<sup>3</sup>, Massimo Chessa<sup>4</sup>, Frank van Buuren<sup>5</sup>, Pedro Trigo Trindade<sup>6</sup>, Domenico Corrado<sup>7</sup>, Hein Heidbuchel<sup>1,2</sup>, Gary Webb<sup>8</sup>, Johan Holm<sup>9</sup>, and Michael Papadakis *European Heart Journal (2013) 34, 3669–3674*

#### **Recommendations for organization of care for Adults with congenital heart disease and for Training in the subspecialty of 'Grown-up Congenital Heart Disease' in Europe: a position Paper of the Working Group on Grown-up Congenital Heart Disease of the European Society Of Cardiology**

Helmut Baumgartner<sup>1\*</sup>, Werner Budts<sup>2</sup>, Massimo Chessa<sup>3</sup>, John Deanfield<sup>4</sup>, Andreas Eicken<sup>5</sup>, Johan Holm<sup>6</sup>, Laurence Iserin<sup>7</sup>, Folkert Meijboom<sup>8</sup>, Jorg Stein<sup>9</sup>, Andras Szatmari<sup>10</sup>, Pedro T. Trindade<sup>11</sup>, and Fiona Walker<sup>12</sup>, for the Working Group On Grown-up Congenital Heart Disease of the European Society of Cardiology *European Heart Journal (2014) 35, 686–690*

Guidelines participation

#### **Hypertrophic cardiomyopathy guidelines** review

WG officially affiliated to a journal? Which one?

### Sessions

(For sessions, please precise titles and accepted/rejected status)

#### **Accepted sessions Barcelona 2014 below**

Clinical Seminar	03.21 - Adult congenital heart disease	Innovative devices for heart failure in adults with congenital heart disease
Clinical Seminar	03.21 - Adult congenital heart disease	The atrial septal defect: do we know everything?

Symposium	03.21 - Adult congenital heart disease	The impact of interventional procedures in ACHD
Symposium	03.21 - Adult congenital heart disease	Pulmonary vascular disease and the Fontan circulation: new paradigms
Symposium	03.21 - Adult congenital heart disease	Marfan Syndrome: new insights
Clinical Seminar	03.21 - Adult congenital heart disease	The challenge of pregnancy in GUCH and CMP
Symposium	03.21 - Adult congenital heart disease	Innovative interventions in ACHD
Meet the experts	03.21 - Adult congenital heart disease	Challenging cases in ACHD
Clinical seminar	03.21 - Adult congenital heart disease	Innovative devices in ACHD

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

## **Other**

Task Force(s)  
Registry / Survey  
**ROPAC pregnancy registry**  
Accreditation programme

## **What are your perspectives for the next 3-5 years**

### **List your future projects / business plan**

Position paper (1) Heart failure in Adult congenital heart disease, Fiona Walker  
Position paper (2) Pregnancy in congenital heart disease, Jolien Roos Hesselink

### **Prepare your budget**

- List your Income: Please specify amount & purpose (from ESC entities & from Industry sponsorship)
- List your main expenses: Please specify amount & purpose

Nucleus meeting at the ESC congress and during the WG annual meeting.



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Annual ESC WG meeting

### **Any Other Business**

Book series on GUCH in collaboration with Springer verlag

## Provide us a SWOT analysis of your Working Group

### **Strength**

Increasing number of members (currently 341)  
Good representation from major centres in Europe in the nucleus  
Annual meeting in GUCH during the last 5 years organized together with other organisations (in 2014 EACTS and ISACHD)  
Good publication of position papers  
Increasing collaboration with other working groups (EACTS, EHRA for position paper, ISACHD, EACVI for echo course and MRI meeting)  
Good collaboration with pediatric cardiology (AEPC) with ESC representation in the AEPC Council since 2013 (currently Johan Holm)

### **Weakness**

Many GUCH meetings organised by national centres are competing with the ESC working group which gives less participation.  
Little research projects organized by the working group  
Annual meeting is only endorsed by the WG and not an official ESC meeting  
Poor information in newsletter to WG members

### **Opportunity**

Growing working group with participation from major centres can have big impact  
Annual ESC meeting organised by the WG in London 2015 instead of an endorsed meeting can give greater visibility outside and within the ESC.

### **Threaten**

Other organizations as e.g. ISACHD take over as a GUCH organisation  
Split of the GUCH community into individual hospitals or university centres.  
Difficult to get input to the ESC from a small working group  
Complicated organization of the ESC with very little communication with leading officers  
Difficult to publish position papers



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### **Address your recommendations/suggestions to the ESC for the next 2 years**

The GUCH working group has developed well over the last two years with increasing number of members and a strong representation of leading GUCH cardiologists in the nucleus.

One challenge is for the WG to be able to organize our annual meeting without depending on other organisations or working groups. We have had problems with the ESC/Heart House to accept our meetings as official ESC meetings. The paperwork and contract was very complicated and often resulted in local organizers doing the meeting on their own. This should be smoother, and annual ESC WG meeting should be encouraged.

Information to the WG members on the ESC web page is difficult to get in and sent to the members. On one occasion we wrote a newsletter, but this was never put in the website or sent out. This should be improved. WG members should get emails from the WG directly.

Communication between the WG and the vice president for working groups is very sparse, and only occurs at the spring summit. There should be an individual meeting between the chairman of the WG and the vice president at the spring summit or at least yearly for information exchange. A dialogue is needed between working groups and central ESC officials.

It is difficult to cooperate between national centres to promote the ESC and what we do. Many of our members feel that the ESC is big and anonymous. Many feel that working with GUCH outside the ESC is easier were you can promote yourself and the centre or university you represent. I keep telling my nucleus that indeed, we are the ESC, and we should be proud of that and work together. This is the challenge, and we need backup and encouragement for that.

Johan Holm  
MD. Associate prof. FESC  
Chairman of the GUCH working group