

# ANNUAL SCIENTIFIC REPORT 2003 - 2004

## ESC WORKING GROUP ON GROWN-UP CONGENITAL HEART DISEASE (WG #22)

'**Adult Congenital Heart Disease is a Subspecialty**', said J. - P. Bassand, ESC-President during the opening ceremony at the annual congress in Vienna 2003. This statement is a great gratitude to all of us dedicated to adult congenital heart disease and acknowledges our predecessors for their leadership and their efforts in the promotion and advancement of our objectives.

During the year 2003-2004, the main focus of our activities was to strengthen the existing ties among the different WGs / Associations and Societies and to create new ties with people who are interested in the care of adult congenital heart disease.

### Objectives of the WG on Grown-Up Congenital Heart Disease:

- To promote, to maintain and to pursue excellence in the care of adults with congenital heart disease;
- To improve the quality of care by endorsing, supporting and organizing educational programmes in adult congenital heart disease;
- To establish guidelines for the treatment and management of adults with congenital heart disease.
- To establish close links with other groups/societies dealing with adult congenital heart disease patients.

### WG 22 Board Members

Prof. John Hess (Munich, CH) resigned as Nucleus Member at the annual ESC congress in Vienna and was succeeded by Prof. Fernando Picchio (Bologna, IT). Otherwise, the Board has not changed.

#### WG 22 Board Members:

- **Chairman:** Erwin Oechslin, Zurich (CH)
- **Vice-Chairman:** Harald Kaemmerer, Munich (DE)
- **Past-Chairman:** Ulf Thilén, Lund (SE)
- **Secretary:** Luciano Daliento, Padova (IT)
- **Treasurer:** Helmut Baumgartner, Vienna (AT)
- **Nucleus Members:** John E. Deanfield, London (GB)  
Rafael Hirsch, Petah Tikva (IL)  
Jana Popelova, Praha (CZ)  
Erik Thaulow, Oslo (NO)  
Fernando Picchio, Bologna (IT) – AEPC representative  
(appointed by the AEPC)

### Annual Scientific Meeting in Munich 2004

Our Cluster includes (no change):

- WG Hypertension and the Heart;
- WG Developmental Anatomy and Pathology
- WG Myocardial and Pericardial Diseases;
- WG Cardiovascular Surgery;
- WG on Grown-Up Congenital Heart Disease.

Erik Thaulow, Oslo (NO) is representative of our Cluster in the Science Council.

Twenty-two of 526 proposals (4%) for pre-arranged sessions were submitted by the Board Members (n=11) and our WG Members (n=11), respectively, and were assigned to the topic 'congenital heart disease / paediatric cardiology'.

Unfortunately, every topic group (Cluster) could organize fewer sessions for Munich than for Vienna. Although only three sessions were assigned to WG 22, we were successful to obtain 4 pre-arranged GUCH sessions for the Munich congress. If the Euro Heart Survey session and pre-arranged sessions of other WGs covering congenital heart disease topics are added, we have 7 congenital heart disease sessions in Munich!

I appreciate the excellent support given by several CPC members who are aware of the increasing importance of our field. Special thanks to Prof. Erik Thaulow, Oslo (NO), who is representative of our Cluster in the Science Council.

### **Congenital Heart Disease Sessions in Munich 2004**

- Pre-arranged congenital heart disease sessions 4
- Euro Heart Survey Session 1
- Other sessions covering congenital heart disease 2
- Abstract sessions 3
- Poster sessions 1

### **Pre-arranged GUCH Sessions at the annual ESC congress in Munich**

- Adult congenital heart disease is a cause of chronic heart failure (Symposium). This is a Joint ESC-GUCH / ISACCD session;
- Recent innovations in ventricular septal defect closure (Clinical Seminar);
- Timing of operations in grown-up congenital heart disease patients (Symposium);
- Pulmonary hypertension in congenital heart disease – new therapeutic aspects (Clinical Seminar).

### **European Heart Survey on Adult Congenital Heart Disease at the annual ESC congress in Munich**

- Clinical management of congenital heart disease in Europe: the Euro Heart Survey (Clinical Seminar).

### **Other sessions covering congenital heart disease at the annual ESC congress in Munich**

- Understanding congenital ventricular arrhythmias: basic science meets the clinician (Symposium Bench to Bedside);
- New contributions of cardiovascular magnetic resonance to congenital heart disease (Symposium).

### **Abstract Sessions**

- Percutaneous interventions in congenital heart disease
- Congenital heart disease: secondary challenges after early 'repair' (Featured Research)

### **Poster Sessions**

- Poster Display IV: Grown-up and congenital heart disease (Poster N° 3545 – 3577)

## **Activities Run Outside the ESC Annual Congress**

### **a) Meetings**

EuroEcho 7 – December 3-6, 2003 in Barcelona

EuroEcho 7 was a very successful congress for WG22. Both the congenital heart disease programme and the high attendance rate reflect the increasing awareness of our subspecialty in the cardiology community and the need to improve the knowledge and expertise in our field – congenital heart disease is getting popular!

Scientific programme (GUCH topics):

- a) Course on Adult Congenital Heart Disease:
- The basics of echocardiography in adults with congenital heart disease
  - Complex lesions (Part 1)
  - Complex lesions (Part 2)

This one-day course was jointly organised by WG 22 and the WG on Imaging of the AEPC. Anatomic / morphologic and echocardiographic correlations were illustrated by pathologists (S.Y. Ho, London, GB; G. Thiene, Padua, IT) and cardiologists. The high attendance rate during the whole day (there was overflow!) is a tribute to the popularity of this one-day course.

- b) Symposia:
- ASD closure – what echocardiography needs to provide
  - The right ventricle – no longer a black box?
  - The univentricular heart (Fontan physiology)
  - Echo-based management of postoperative congenital heart disease
- c) Teaching Course:
- How to investigate the operated patient with congenital heart disease
- d) DICE Session:
- Pearls in congenital heart disease
  - Challenging cases in paediatric congenital heart disease (this session was organised by AEPC / paediatricians from Poland).
- e) Poster (n=1) Session entitled 'Congenital Heart Disease'.

3<sup>d</sup> Joint European / North American Symposium on Congenital Heart Disease in the Adult  
September 19-20, 2003; Santorini, Greece

This meeting was in honour of Joseph K Perloff, UCLA, for his major contribution to congenital heart disease. Michael Gatzoulis honoured him as a clinician, as a scientist and as a teacher of excellence! There was a Joint ESC-GUCH / ISACCD session at this highly interactive and focused meeting on congenital heart disease.

XXXIX Annual Meeting of the Association for European Paediatric Cardiology  
May 19-22, 2004, Munich, Germany

There was a Joint AEPC / ESC-GUCH session entitled 'Anticonception and Pregnancy Counseling in GUCH – Do we do our job?' J. Deanfield and F. Picchio organized a very well attended session.

**b) ESC Pocket Guidelines: Management of Grown Up Congenital Heart Disease**

The first European Task Force Document on the Management of Grown-Up Congenital Heart Disease published in 2003 (*Eur Heart J* 2003; 24:1035-1084) is a key manuscript for high quality care of adults with congenital heart disease! An editing committee wrote the ESC pocket guidelines in spring.

Editing committee of the pocket guidelines:

- Prof. A. Hoffmann, Basel (CH), project coordinator
- Prof. J. Deanfield, London (GB)
- Prof. H. Kaemmerer, Munich (DE)
- PD Dr. E. Oechslin, Zurich (CH)

### ***c) Collaboration with ESC-WGs, AEPC and ISACCD***

The fruitful activities of WG 22 have been continued and the ties with other ESC-WGs and other international societies have been strengthened. A close cooperation among associations and their members helps to transfer knowledge and expertise!

#### ESC-WGs

There was a close interaction, discussion and collaboration with many WG representatives, especially with Nucleus Members of the following WGs/Association during the preparation process for the Annual ESC Meeting 2004:

- Cardiovascular Surgery;
- Myocardial and Pericardial Diseases;
- Rehabilitation and Exercise Physiology;
- Developmental Anatomy and Physiology, and others.....

#### European Association of Echocardiography (EAE)

There was a very close collaboration for the preparation of EuroEcho 7 (Fausto Pinto, President, and Alan Fraser, Vice-President).

#### Association for European Paediatric Cardiology (AEPC)

The very successful collaboration with AEPC has been continued. Prof. Fernando Picchio, Bologna (IT) is the new AEPC representative within our Nucleus. Prof. J. Deanfield is responsible for relations to AEPC. There were very fruitful and stimulating discussions between O. Daniels, AEPC President 2001-2004, I. Oberhaensli-Weiss, AEPC Secretary General and me.

#### International Society for Adult Congenital Cardiac Disease (ISACCD)

The Joint Sessions at the annual ESC meetings reflect the close collaboration and interaction between ISACCD and ESC-GUCH representatives. **Michael A. Gatzoulis** (WG 22 Member), London (GB) is the **first European ISACCD president** in charge (2004-2006). Erwin Oechslin (Chairman WG 22) was elected to serve as ISACCD treasurer in the years 2004-2006.

#### Canadian Congenital Heart Network (CACH Network)

There has been a very close and successful cooperation for many years. I am very grateful to Prof. Gary Webb, President of the CACH Network, Toronto, for his stimulating collaboration!

### **Membership**

The total number of WG 22 membership has increased to 196 active members at the date of August 15, 2004. There has been an increase in 6 members since August 2003:

- PD Dr. Urs Bauersfeld, Hospital for Sick Children, Zurich (CH)
- Dr. Pedro Trigo Trindade, Centre Cardiologie, Hôpital Universitaire de Genève, Geneva (CH)

- Prof. Jacek Bialkowski, Congenital Heart Disease & Paediatric Cardiology, Silesian Center for Heart Disease, Zabrze (PL)
- PD Dr. Christine Attenhofer Jost, FESC, CardioVascular Center, Klinik im Park, Zurich (CH)
- PD Dr. Franz Robert Eberli, Director of Invasive Cardiology, CardioVascular Center, University Hospital, Zurich (CH)
- PD Dr. Felix Berger, Hospital for Sick Children, Zurich (CH)

## Registry on Arrhythmias in Congenital Heart Disease

There are data regarding arrhythmias, management strategies and outcome in adults with congenital heart disease, but we need better ones. This is the reason why a Study Group was established to create a Registry on Arrhythmias in patients with congenital heart disease.

Members of this Study Group:

- Guenter Stix, Vienna (AT), project leader
- Urs Bauersfeld, Zurich (CH)
- Joachim Hebe, Bremen (DE)
- Bernhard Zrenner, Munich (DE)

The tasks of the study group are:

- To establish a Registry on Arrhythmias in patients with congenital heart disease;
- To manage the database;
- To analyse the data and to report the results;
- To report about the activities and the progress of the registry at the annual WG business meetings.

## European Heart Survey on Adult Congenital Heart Disease

The European Heart Survey (EHS) on Adult Congenital Heart Disease was ***the core activity in 2003 and 2004***. The database was locked on April 30, 2004! Seventy-nine centers (47 specialised and 32 non-specialised centers) participated in the Survey. More than 4'000 patients were included. Barbara Mulder (Amsterdam, NL), Chairperson of this Survey, and her team (Research Fellows: Tanja Meggens, Peter Engelfriet) and staff at the European Heart House did an excellent job and made this EHS to a success. Their contribution and initiatives are highly appreciated! On behalf of the Nucleus and of the Expert Committee, I owe a great debt of gratitude to all colleagues who included patients and have contributed to this Survey. Their input and their excellent support are highly appreciated!

The first results of this EHS will be presented at the annual congress 2004 in Munich.

## Study Group of 'Sports Cardiology'

ESC has established a study group on 'Sports Cardiology' within the WGs of Cardiac Rehabilitation and Exercise Physiology. Hans Björnstad (Haukeland University Hospital, Bergen, NO) chairs this study group. Prof. Andreas Hoffmann, Basel (CH) represents WG 22.

The document '*Recommendations for participation in competitive sports in athletes with cardiovascular disease – a consensus document*' will be prepared. A. Hirth, T. Reybrouck, B. Bjarnason-Wehrens, W. Lawrenz and A. Hoffmann have written the recommendations for the subtopic *Congenital Heart Disease*; a final draft version of this subtopic is ready.

## **Future Perspectives – The Chairman’s Message**

Our structural and political environment is changing! The constitutional review of the ESC and the creation of a new structure – **Associations** – have opened new options to promote our objectives.

All bodies acting in the field of congenital heart disease must strengthen their structural power to be more efficacious, to be even more successful in completion of their objectives and to fight for their common interests in the near future! An option may be to merge the different bodies, which are involved in congenital heart disease, to a **European Association on Congenital Heart Disease and Surgery**. A European Association on Congenital Heart Disease and Surgery would serve as the leading organisation in the field of congenital heart disease in Europe, and would attract all physicians from Europe to foster the development of this area of expertise! This restructuration process would bring all bodies involved in congenital heart disease together at a European level:

- To strengthen the common interests in the field of congenital heart disease;
- To promote, to maintain and to pursue excellence in the care of patients with congenital heart disease from childhood until adulthood;
- To share and to improve the special knowledge available in the different fields (paediatric cardiology, GUCH cardiology, congenital heart surgery);
- To enhance congenital heart disease issues at a European level;
- To strengthen the political and financial power.

Let’s start the discussion sooner rather than later!

## **Acknowledgement**

I appreciate all activities of our WG members to improve the care for adults with congenital heart disease and I am indebted to the Nucleus Members for their stimulating discussions and excellent support!



Erwin Oechslin, MD, FESC  
Chairman WG on Grown-Up Congenital Heart Disease