

ANNUAL SCIENTIFIC REPORT 2004 - 2005
ESC WORKING GROUP ON GROWN-UP CONGENITAL
HEART DISEASE (WG #22)

1. 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 programs in adult congenital heart disease;
- To establish close links with other groups/societies dealing with adult congenital heart disease patients.
- To promote research in the field of adult congenital heart disease
- To establish guidelines for the treatment and management of adults with congenital heart disease.

The ambition of the ESC Working Group on Grown-Up Congenital Heart Disease (WG 22) is to serve as the leading organization in the field of adult congenital heart disease in Europe and to attract all physicians to foster the development of this area of expertise.

2. STRUCTURES AND ORGANISATION

2.1. Our Cluster includes (no change):

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

O. Oto, Past-Chairman of WG 25, Izmir (TR) is currently the representative of our Cluster in the Science Council.

2.2. During the year 2004/2005, the Nucleus of the WG has been composed as follows:

- **Chairman:** Harald Kaemmerer, Munich (DE)
- **Vice-Chairman:** Helmut Baumgartner, Vienna (AT)
- **Past-Chairman:** Erwin Oechslin, Zurich (CH)
- **Secretary:** Jana Popelova, Praha (CZ)
- **Treasurer:** Folkert Meijboom, Rotterdam, (NL)

- **Nucleus Members:** Luciano Daliento, Padova (IT)
John E. Deanfield, London (GB)
Rafael Hirsch, Petah Tikva (IL)
Ulf Thielén, Lund (SE)
Fernando Picchio, Bologna (IT) – AEPC representative
(appointed by the AEPC)
- **Honorary Member:** Jane Somerville, London (GB)

Prof. Erik Thaulow, Oslo (NO) resigned as Nucleus Member at the annual ESC congress in Munich.

2.3. Membership

The total number of WG 22 membership has increased to more than 200 active members at the date of July 2005.

3. ACTIVITIES OF THE WORKING GROUP 2004 – 2005

During the year 2004-2005, a main focus of our activities was to further 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.

Throughout the year WG 22 was involved in several collaborative meetings and projects. Without any doubt the Euro Heart Survey on adult congenital heart disease was one of the highlights (see below).

3.1. INTERNATIONAL CONGRESSES and MEETINGS

3.1.1. Annual ESC-Congress in Munich 2004

WG 22 was able to obtain 4 pre-arranged GUCH sessions plus 1 Euro Heart session and if we add 2 sessions of other WG covering the field of CHD, there were 7 pre-arranged congenital heart disease Sessions in Munich.

3.1.2. Joint Meetings With Other Organizations And Societies

Several members of WG 22 were heavily represented as speakers and chairmen on the following international meetings:

- EuroEcho 8 – Athens, Greece, December 1-4, 2004. There was a very close collaboration with the European Association of Echocardiography (EAE) (Fausto Pinto, and Alan Fraser) for the preparation of EuroEcho 8. The congenital heart disease program reflected the increasing awareness of our subspecialty in the cardiology community and the need to improve the knowledge and expertise in our field.
- Adult Congenital Heart Disease. Tokyo, Japan January 2005

- International Symposium on Congenital Heart Disease in the Adult, Toronto, Canada, May 26 – 28, 2005
- DACH-Symposium (Germany, Austria, Switzerland) on adult congenital heart disease, Zurich, July 1 and 2, 2005.
- Heart Failure Meeting 2005 in Lisbon (June 11-14), organized by the Heart Failure Association of the ESC.

3.2. UPCOMING MEETINGS

3.2.1. ESC Congress in Stockholm, 3 – 7 September 2005

Seventeen of 517 proposals (3,3 %) for pre-arranged sessions were submitted by the Board Members and our WG Members, respectively, and were assigned to the topic '*congenital heart disease / pediatric cardiology*'.

Every topic group (Cluster) could organize fewer sessions for Stockholm than for Munich. We were successful to obtain several pre-arranged GUCH sessions for the Stockholm congress.

Special thanks to Prof. Öztekin OTO, Izmir (TR), who acted as cluster-coordinator and presented our proposals to the Congress Programme Committee.

Moreover, we appreciate the excellent support given by András SZATMARI, Budapest (HU) and the other Congress Programme Committee members who are aware of the increasing importance of our field.

3.2.2. EuroEcho 9 – Florence, Italy, December 7-10, 2004

Again, there was a very close collaboration with the European Association of Echocardiography (EAE) for the preparation of EuroEcho 9.

4. ACTIVITIES RUN OUTSIDE THE ESC ANNUAL CONGRESS

4.1. European Heart Survey on Adult Congenital Heart Disease:

Members of WG 22 formed the Scientific Committee of the **Adult Congenital Heart Disease** Survey under the chairmanship of Barbara Mulder (NL).

The Euro Heart Survey on CHD was finished in April 2004. 4168 adult patients with CHD could be recruited from 79 centers in 26 countries. Because of the low prevalence and many different diagnosis of CHD, the study was designed as retrospective cohort study with 5-year follow-up. The results showed that the clinical practice is fairly consistent with (flexible) guidelines for intervention. Guidelines for diagnostics are followed in 50-60 % of cases. Drug treatment is close to targets. The mortality was high in Fontan patients and cyanotic CHD, but relatively low in other defects. Two papers are in press (European Heart Journal).

4.2. 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, not only in Europe!

An editing committee (Prof. Dr. A. Hoffmann, Basel (CH); Prof. J. Deanfield, London (GB); Prof. Dr. Dr. H. Kaemmerer, Munich (DE); PD Dr. E. Oechslin, Zurich (CH)) composed the ESC pocket guidelines, which will appear during the Stockholm meeting, 2005.

4.3. **Collaboration with ESC-WGs, AEPC and ISACCD**

The fruitful cooperation of WG 22 with ESC-WGs and other international societies has been strengthened in order 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:

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

Association for European Pediatric Cardiology (AEPC): The very successful collaboration with AEPC has been continued. Prof. Fernando Picchio, Bologna (IT) is the AEPC representative within our Nucleus. Prof. J. Deanfield is responsible for relations to AEPC. There were very fruitful and stimulating additional discussions with the AEPC-President Prof. A. Szatmary (HU).

International Society for Adult Congenital Cardiac Disease (ISACCD): The tight cooperation between ISACCD and ESC-GUCH representatives persists. **Michael A. Gatzoulis** (WG 22 Member), London (GB) is the **first European ISACCD president** in charge (2004-2006) and Erwin Oechslin (Past-Chairman WG 22), Zurich (CH) is currently ISACCD treasurer.

Canadian Congenital Heart Network (CACH Network): Also this very close and successful cooperation continues!

5. **UPCOMING PROJECTS**

Several study groups dealing with specific problems regarding adults with congenital heart disease have been established. Their task is:

- To establish specific registries in patients with congenital heart disease
- To manage the database

- To analyze the data and to report the results
- To report about the activities and the progress of the registry at the annual WG business meetings.

Registry on Arrhythmias in Adult Congenital Heart Disease

A task force has been established to create a registry on Arrhythmias in adults with congenital heart disease to collect data regarding arrhythmias, management strategies and outcome in adults with congenital heart disease.

Members of this task force: Günter Stix, Vienna (AT), project leader; Urs Bauersfeld, Zurich (CH); Joachim Hebe, Bremen (DE); Bernhard Zrenner, Munich (DE).

Registry on Pregnancy in Adult Congenital Heart Disease

A task force has been established to create a registry on pregnancy in patients with congenital heart disease to collect data regarding course, management strategies and outcome in adults with congenital heart disease.

Members of this Study Group: Jörg Stein, Innsbruck (AT), project leader.

Register of Adult Congenital Heart Disease-Centers in Europe

A task force has been established to collect data regarding the localization and infrastructure of Adult Congenital Heart Disease-Centers in Europe.

Members of this Study Group: Harald Kaemmerer, Munich (DE), project leader; Helmut Baumgartner, Vienna (AT); Erwin Oechslin, Zurich (CH).

Study Group of ‘Sports Cardiology’

ESC has established a study group of ‘Sports Cardiology’ within the WGs of Cardiac Rehabilitation and Exercise Physiology and Myocardial and Pericardial Diseases. Prof. Andreas Hoffmann, Basel (CH) represents WG 22.

The document *‘Recommendations for competitive sports participation in athletes with cardiovascular disease – a consensus document* from the Study Group of Sports Cardiology of the Working Group of Cardiac Rehabilitation and Exercise Physiology and the Working Group of Myocardial and Pericardial Diseases of the European Society of Cardiology’ has been published (Eur Heart J 2005; 26:1422-1445). A. Hirth, T. Reybrouck, B. Bjarnason-Wehrens, W. Lawrenz and A. Hoffmann have written the recommendations for the subtopic *Congenital Heart Disease*.

6. ACKNOWLEDGEMENT

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

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Erwin Oechslin, PhD, MD, FESC

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