

ANNUAL SCIENTIFIC REPORT 2002 - 2003

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

The evolving field of adult congenital heart disease is challenging. It is more difficult for us to get logistical or financial support than for others to achieve our goals; our subspecialty may not be as attractive as others may be. Thus, a close collaboration among the members and among other societies dealing with congenital heart disease is the key for success.

WG 22 Board Members

WG 22 Board was elected in September 2002. The suggested composition of the Board was accepted by the great majority of the voting members.

Prof. Frantisek Kolbel (Praha, CZ) retired. We are indebted to his contributions to the field of adult congenital heart disease. His successor is Jana Popelova, Praha (CZ).

WG 22 Board Members:

- **Chairman:** Erwin Oechslin, Zurich (CH)
- **Vice-Chairman:** Harald Kaemmerer, Munich (DE)
- **Past-Chairman:** Ulf Thielén, 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)
John Hess, Munich (DE) – AEPC
representative (appointed by the AEPC)

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.

Annual Scientific Meeting in Vienna 2003

Twenty-three proposals for pre-arranged congenital heart disease sessions were submitted by the Board Members and our WG members, respectively. We were successful to obtain 6 pre-arranged GUCH sessions for the Vienna meeting. The successfully submitted 1st Joint Session ESC-GUCH /

ISACCD entitled 'heart disease and pregnancy' was modified by the Programme Committee during the final evaluation process.

Our Cluster includes:

- WG Hypertension and the Heart;
- 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.

Congenital Heart Disease Sessions in Vienna 2003

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| • Pre-arranged GUCH sessions in Vienna | 6 |
| • Other sessions dealing with 'congenital heart disease' | 3 |
| • Abstract sessions | 2 |
| • Poster sessions | 4 |

Pre-arranged GUCH sessions at the annual ESC meeting in Vienna 2003

- Who should close atrial septal defects: surgeons, cardiologists or robots? (Clinical Seminar);
- Marfan syndrome: medical, interventional and surgical treatment options (Symposium);
- Management of grown-up congenital heart disease in Europe: task force guidelines and their implications (Clinical Seminar);
- Transposition of the great arteries: morphology, late complications and management (Symposium);
- Electrical treatment and pitfalls in grown-up congenital heart disease (Clinical Seminar);
- Pregnancy and heart disease (Main Session).

Other sessions dealing with congenital heart disease

- Recent insights into mechanisms of cardiac development: new perspectives for congenital heart disease (Basic Science Track in collaboration with AEPC);
- Patent foramen ovale: from evaluation to treatment: Live from Vienna (Focus Session);
- Cardiac Anatomy and Pathology LIVE:
WG 17 (Developmental Anatomy and Pathology) has invited us to participate in this session. There will be a live-video and hands-on demonstration to illustrate directly the subject and then to give the chance to cardiologists to look directly to heart specimens. Prof. Gaetano Thiene will also dedicate this exhibition to congenital heart disease.

Abstract Sessions

- Late findings after treatment for congenital heart disease (Programme N° 125-130)
- Heart function in congenital heart disease (Programme N° 1865-1870)

Poster Sessions

- Arrhythmias in congenital heart disease (Programme N° 388 – 397)
- Interventions in congenital heart disease (Programme N° 577 – 587)
- Cardiac interventions: valves, congenital heart disease (Programme N° 588 – 598)
- Metabolic aspects in congenital heart disease (Programme N° 3414 – 3423)

Activities Run Outside the ESC Annual Congress

a) Task Force: Management of Grown Up Congenital Heart Disease

The first European Task Force Document on the Management of Grown up Congenital Heart Disease was recently published (*Eur Heart J* 2003; 24:1035-1084). This document is a key manuscript for a high quality care of adults with congenital heart disease! I am indebted to all members of the Task Force for their hard and excellent work. A special thanks to Prof. John Deanfield (London, GB), Chairman of this Task Force, for his perseverance and energy to make this document a success!

This Task Force document is available at: <http://www.esccardio.org/scinfo/Tforceguidelines.htm>

b) Meetings

1st Joint European / North American Symposium on Congenital Heart Disease in the Adult - September 26-28, 2002, in London (GB)

This was the first Joint European / North American Symposium in Adult Congenital Heart Disease endorsed by the WG on GUCH of the ESC. The Programme Directors were: Michael A. Gatzoulis, London (GB), Daryl F. Shore, London (GB), and Gary D. Webb, Toronto (ON, Canada). WG 22 members were in the scientific committee and / or invited speakers at this highly interactive and focused meeting on adult congenital heart disease. It will be organised every year and substantially contribute to the education in our expanding field of expertise!

EuroEcho 6 - December 4-7, 2002, in Munich (DE)

Four joint sessions/symposia (with WG on Echocardiography) and one DICE session were organized:

- Tetralogy of Fallot: the subpulmonary right ventricle
- Transposition complexes: the systemic right ventricle
- Advances in imaging adults with congenital heart disease
- Vascular/endothelial function
- DICE session

There were also two abstract sessions.

38th AEPC Annual Meeting - May 28-31, 2003, in Amsterdam (NL)

There was a GUCH session entitled '*Emergencies in Adult Congenital Heart Disease*' at this annual meeting organized by our AEPC representative John Hess (Munich, DE).

D-A-CH Symposium: Congenital Heart Disease in the Adult - May 16-18, 2003, in Munich (DE)

This was the first international symposium in the German speaking countries of Europe scientifically supported by three National Working Groups on Grown Up Congenital Heart Disease (D = Germany, A = Austria, CH = Switzerland). This meeting will be organized every two years in Germany, Switzerland and Austria on alternate basis. This meeting was also endorsed by the WG on GUCH of the ESC.

c) Collaboration with other ESC-WGs, AEPC, CACH Network and ISACCD

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 during the preparation process for the Annual ESC Meeting 2003 and for EuroEcho:

- Echocardiography
- Myocardial and Pericardial Diseases;
- Cardiovascular Surgery;
- Myocardial and Pericardial Diseases;
- Arrhythmias / Cardiac Pacing;
- 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 among AEPC and ESC-GUCH committee members. Prof. John Hess (Munich, DE), AEPC representative in our Nucleus, is the key person promoting this very fruitful cooperation.

International Society for Adult Congenital Cardiac Disease (ISACCD)

There was an informal meeting among representatives of ISACCD and ESC-GUCH at the 1st Joint North American / European symposium on adult congenital heart disease in London in September 2002. There is a mutual agreement to organize ***ESC-GUCH / ISACCD Joint Sessions*** at the annual meetings of the ESC and of the AHA or ACC (one joint session in Europe and one in the USA per year).

Canadian Congenital Heart Network (CACH Network)

There has been a very close and successful cooperation for many years: ESC-GUCH members were panelists in the Canadian Consensus documents 1996 and 2001, GUCH cardiologists were in the guest faculty of the 14th Annual International Symposium on Congenital Heart Disease in the Adult 2003 which had to be cancelled because of perception regarding the SARS situation in Toronto.

Membership

The total number of WG22 membership has increased to 190 active members at the date of August 10, 2003. There has been an increase in 5 members since August 2002:

- Dr. Wei Li, Adult CHD & Echocardiography, Royal Brompton Hospital, London (GB)
- Prof. R. Prêtre, Congenital Cardiac Surgery, University Hospital, Zurich (CH)
- Prof. Mirta Kozelj, Dept. of Cardiology, University Medical Centre Ljubljana, (SL)
- Dr. Roberto Crepaz, Dept. of Cardiology, Regional Hospital of Bolzano, Milano (IT))
- Dr. Massimo Chessa, Pediatric Cardiology, Istituto Policlinico San Donato, Milano (IT)

European Heart Survey on Adult Congenital Heart Disease

This Survey is one of the core activities of our Working Group during the next years! Barbara Mulder (Amsterdam, NL), Chairperson of the Euro Heart Survey on Adult Congenital Heart Disease, and Tanja Megens (Amsterdam, NL), Research Fellow for this Survey, have invested their energy to get the Survey started in Spring 2003 and to make it a success! More than 100 centers spread over 29 countries in Europe have given their commitment to participate in this Survey. The aim of this Survey is to recruit a total of 5600 patients, i.e. 700 patients per defect, by the end of 2003.

We are indebted to Barbara Mulder and Tanja Megens for their commitment to this Survey and their outstanding work.

Study Group on 'Sports Cardiology'

WG 22 was invited to have a representative in this study group which is chaired by Hans Björnstad (Haukeland University Hospital, Bergen, NO). Prof. Andreas Hoffmann, Basel (CH) has been elected to represent WG 22.

The tasks of this study group are:

- To make proposals for symposia at the ESC congress;
- To organize teaching courses;
- To make recommendations/guidelines regarding eligibility for sports activities in cardiovascular disease;
- To stimulate scientific projects / organize multicentre studies.

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