

March, 2009

Adult Congenital Heart Disease Working Group Report of Activities

Adult Congenital Heart Association Medical Advisory Board Report of Activities

Report from the Adults with Congenital Heart Disease (ACHD) Committee of the Councils on Cardiovascular Disease in the Young (CVDY) and Clinical Cardiology (CLCD)

International Society of Adult Congenital Heart Disease Update

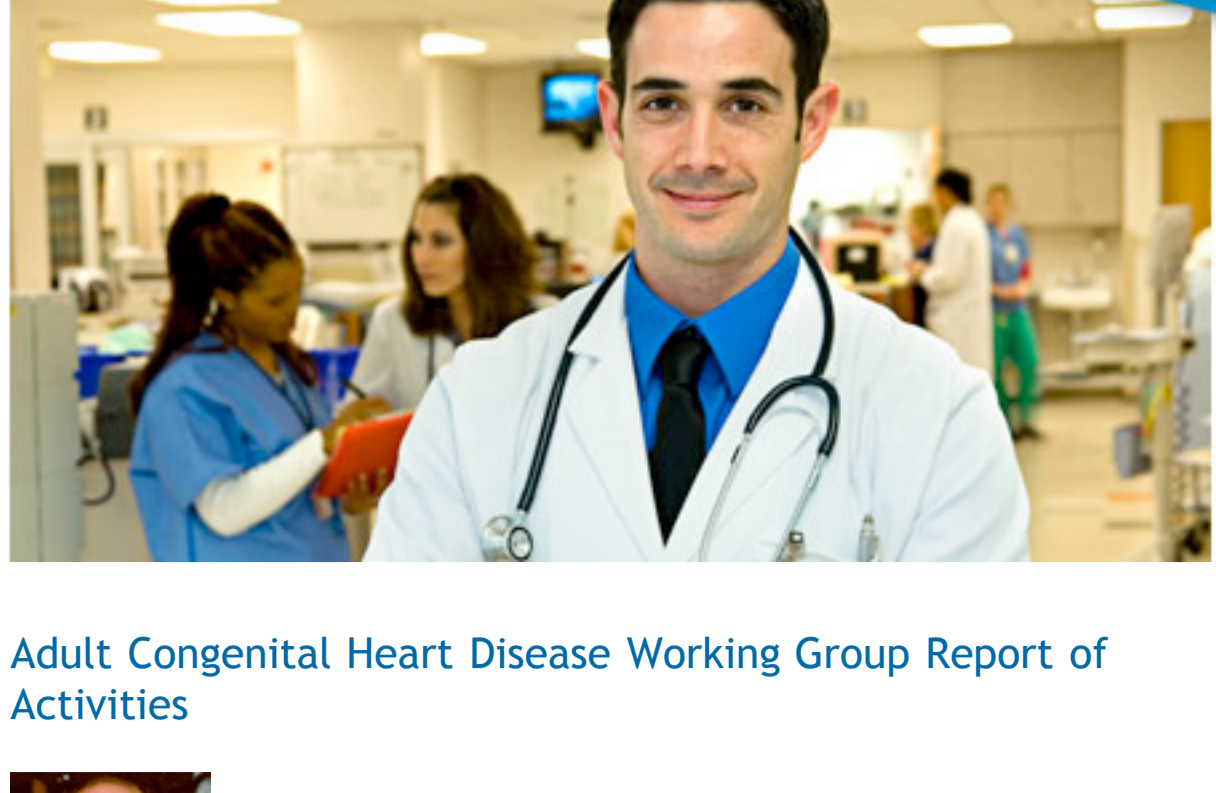
Working Group on Grown-Up Congenital Heart Disease of the European Society of Cardiology (WG 22)

The *Global Update Newsletter* serves as a bi-annual communication avenue for professionals and corresponding national and international organizations dedicated to the interest of patients with congenital heart disease.

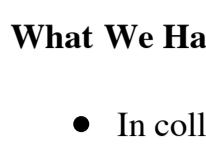
Editors:
Gary Webb, MD, F.A.C.C.
(Chair, ACC ACHD Working Group)

Elyse Foster, MD, F.A.C.C., FAHA (Co-Chair, AHA CVDY Council)

Questions about the publication, please contact Stephanie Mitchell at Smitchel@acc.org



Adult Congenital Heart Disease Working Group Report of Activities



Submitted by Gary Webb, M.D., F.A.C.C., Chair, ACHD WG under the American College of Cardiology's Adult Congenital & Pediatric Cardiology Section

What We Have Done

- In collaboration with the leadership of four other ACHD professional groups, we are planning a newsletter with input from each group, and circulation to all the members of all the groups. The main purpose is to make all interested parties aware of what each group is doing and planning, and to a lesser extent to avoid duplicated effort.
- We were concerned that there was very little ACHD content at AHA 2008 in New Orleans, and recommend that interested ACHD professionals suggest content for future major annual meetings by contacting Dan Murphy, Michelle Gurvitz, Michelle Nickolaus and Karen Stout regarding the ACC program, and contacting Karen Stout and Elyse Foster regarding the AHA program.
- The American College of Cardiology (ACC) has a major commitment to quality care. Within the ACPC (Adult Congenital and Pediatric Cardiology) Council, this work is led by Kathy Jenkins. Curt Daniels represents ACHD in this process. He has recommended that the ACHD metric have to do with obtaining at least one MRI or CT scan for patients who have repaired aortic coarctation.
- The AHA/ACC ACHD Guidelines were published in November 2008, led by Carole Warnes and Roberta Williams, both members of the Working Group. This has been a major achievement as we work towards more evidence-based practice.
- The AARCC multicenter research group has an ongoing relationship with the Working Group, and continues to make very good progress. It has three active large protocols approaching completion, and several others pending. In collaboration with ACHA, it recently received grant support from the NIH for the first time.
- The recently formed Adult Congenital Cardiac Care Associates Research Group is actively developing several research protocols. This non-physician group of ACHD healthcare professionals is committed to multi-center research and it has an ongoing relationship with the ACHD Working Group and AARCC group through Disty Pearson and Michelle Nickolaus.
- The ACC has made a commitment to represent the ACHD community in its dealings with the American Board of Internal Medicine and the American Board of Pediatrics relating to certification of ACHD trained cardiologists. The original effort in January 2008 was led by Gerard Martin and Mike Landberg for the ACPC Council. The current efforts are led by Mike Landberg and Tom Graham, both members of the Working Group. o Roberta Williams has represented the Working Group and the ACHD community at the ACC Legislative Conference. Both she and Tim Garson are members of a blue ribbon ACC working group whose purpose is to improve American health care.

What We Are Planning

- The American College of Cardiology supported the ACHA and its partners for the National Congenital Heart Lobby Day held February 10, 2009 in Washington, DC. The ACC hosted a reception at Heart House on February 9 and arranged for briefing/debriefing at the Capitol Hill Club on February 10.
- Members of the Working Group will continue to work on the topics of ACHD quality metrics and on ACHD healthcare improvements in the USA.
- Dan Murphy and Steve Brabeck will make recommendations on improving the use of the ACHD Guidelines in the general cardiology community.
- The Working Group will discuss how the ACHD Guidelines can be continuously improved and updated based on new scientific evidence.
- The ACHD subspecialty cardiology training and certification work will continue under the leadership of Tom Graham and Mike Landberg. The plan is to have proposals ready for submission by early spring 2009.

[Back to Top](#)

Adult Congenital Heart Association Medical Advisory Board Report of Activities



Submitted by Gary Webb, M.D., F.A.C.C., Chair, ACHD WG under the American College of Cardiology's Adult Congenital & Pediatric Cardiology Section

What We Have Done

- ACHA and AARCC were awarded an NIH grant to coordinate the Health Education and Access Research Trial in Adult Congenital Heart Disease (HEART-ACHD) study. The HEART-ACHD study is scheduled to begin in January and will include AARCC member institutions University of Washington Medical Center, Children's Hospital Boston, Hospital of the University of Pennsylvania, University of Colorado Medical Center, Oregon Health and Sciences University Medical Center, Columbia University Medical Center, Medical College of Wisconsin, Children's National Medical Center, Penn State University Medical Center, Nationwide Children's Hospital, and University of California Los Angeles Medical Center.
- ACHA and ISACHD completed the third edition of the online ACHD Clinic Directory. The Directory now lists 80+ ACHD programs in the United States and Canada.
- ACHA's Lifelong Care Committee began a research project called the Parental Knowledge and Lifelong Care study, lead by Sue Fernandes at Children's Hospital Boston, and including nine other institutions nationally: Nationwide Children's Hospital, University of Florida, UCSF Medical Center, Mattel Children's Hospital, Akron Children's Hospital, Children's Hospital Los Angeles, The Children's Heart Clinic, Miami Children's Hospital, and Penn State Hershey Medical Center. The study involves a baseline survey for parents of children ages 2-18 with four repaired complex heart defects. Once the baseline survey is completed, a lifelong care education campaign will launch. A second survey will be given to different parents to measure the success of the educational campaigns.
- ACHA MAB and Board of Directors members served on the Scientific Committee for Informatics Development, which is working on the CONGENERATE project to create software for ACHD programs that will provide clinic management and scheduling tools, data sharing tools for multi-center research initiatives, and capability for a patient registry. A live web-based demonstration was given 11/11/08 in conjunction with the AHA Scientific Sessions.
- The Publications Committee produced one-page educational articles for clinic use, available on ACHA's website (www.achaheart.org) for download, in addition to producing the Heart Matters Newsletter quarterly.
- MAB member Karen Kuehl addressed ACHD at the Social Security Administration's SSI criteria update forum.

What We Are Planning

- ACHA will kick-off Vision 2020, an effort to identify what needs to be done in the field of American ACHD care over the next 10 years and to accelerate progress in the identified areas.
- The ACHA 09 Boston "US Professionals Conference: Building the Future of ACHD Now" will take place April 24-26, 2009 at the Renaissance Boston Waterfront Hotel
- National Congenital Heart Lobby Day was held February 10, 2009. Participants asked Congress to support legislation for a national CHD registry and CHD research and education.
- We will begin recruitment for the HEART-ACHD and Parental Knowledge and Lifelong Care research studies in January.
- The 2010 Sixth National ACHA Conference for Patient/Family and Health Professionals will be held in Los Angeles, California.

[Back to Top](#)

Report from the Adults with Congenital Heart Disease (ACHD) Committee of the Councils on Cardiovascular Disease in the Young (CVDY) and Clinical Cardiology (CLCD)



Submitted by Co-Chairs Craig Sable, MD FAHA & Elyse Foster, MD FAHA

Three major initiatives for this committee in 2008 included:

1. **AHA Program Development:** At the request of Dr. Alan Kadish who chairs the Clinical Cardiology Council Program Committee, Karen Stout was appointed to represent the ACHD Committee and attended the Clinical Cardiology Program Committee Planning Meeting in December 2008. With the help of the ACHD Committee, she submitted proposals for one Special Session, 3 Cardiovascular Seminars, one Daytime Seminar, 2 Ask the Experts, 2 How To Sessions and one Sunday Morning Program. Elyse Foster will champion these sessions at the CSSP meeting in January. Hopefully, through these efforts ACHD will have an increased presence at AHA 2009.
2. **ACHD Patient Education Pamphlet:** The committee worked hard to adapt the Congenital Heart Disease patient education materials previously available from AHA in print form, to an on-line version specifically focused on the adult population. These materials are in their final stages of revision and will include excellent graphics. Hopefully, they will be available on the AHA Web Site within the next 6 months.
3. **Recommendations for Preparing Adolescents with Congenital Heart Disease for Transition to Adulthood paper:** The committee spearheaded the re-commission of this document. A writing group has been formed and they have had their first meeting with writing assignments. Craig Sable, Elyse Foster and Karen Uzark are chairing this writing group.

[Back to Top](#)

International Society of Adult Congenital Heart Disease Update



Submitted by Michael J. Landberg, M.D., F.A.C.C., President, ISACHD

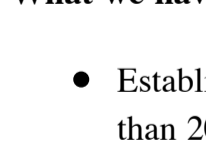
ISACHD continues to push towards its strategic goals FOCUS 2008-2010 Campaign: secure Foundations, enhance Center stability and develop Unified and Sustained awareness.

Towards these goals:

- Secure Foundations: we plan to increase our regional representation with introduction of a new regional representation, as of ACC 2009, from the Middle East, incorporating largest programs from Egypt, Israel and Saudi Arabia, as a start. By working through the existing framework of ISACHD round-tables, we plan to identify needs, and plan an international growth, development and collaboration team that can be a model for other regions.
- Enhance Center Stability: 1) the GOLDEN opportunities slide program is now available to download via the ISACHD website. This slide program emphasizes common pitfalls and goals in ACHD program development. 2) ISACHD continues to support joint efforts with ACHA and CONGENERATE towards design, testing and implementation of an internationally available ACHD database with on-line practical application for small, intermediate and large centers, alike. 3) We have investigated the costs and await further progress FY 2009 towards accomplishment of "ISACHD Rounds" videoconferencing, with goals to be available to all via internet 4) ISACHD supports the pending International Patient Advocacy summit
- Unified/Sustained Awareness: 1) a questionnaire, designed to assess ACHD center resources, and ACHD caregiver needs, is under design, and will be implemented via web-site and email awareness this academic quarter (goal). 2) Committee development towards a) Advocacy, (partnership with local, regional and world health governance organizations, etc) b) Accreditation / Guidelines coordination, 3) Program and communications is underway.

[Back to Top](#)

Working Group on Grown-Up Congenital Heart Disease of the European Society of Cardiology (WG 22)



Submitted by Folkert Meijboom, M.D., Ph.D.

What we have done:

- Established a WG on grown-up congenital heart disease within the ESC more than 20 years ago, with now >220 members throughout Europe. Current chairman is Folkert Meijboom.
- There is a [ESC WG web-page](#) on which activities are published. A special web-editor has been appointed for the first time in 2008, Antonia Pijuan-Domenech, in order to enhance the web-based communications.
- The first ESC guidelines on Grown-ups with congenital heart disease were published in 2003, headed by John Deanfield. These guidelines are now being revised by a new task force, headed by Helmut Baumgartner.
- Recommendations for CMR & congenital heart disease, together with North American society for Adult Congenital Heart Disease, to be released in 2009.
- The ESC textbook of Cardiovascular Medicine, edited by [Camm, Lüscher and Serruys](#), first edition 2006, had a chapter Congenital heart disease, written by John Deanfield, Robert Yates and Vibeke Hjortdal. The textbook is now being revised, including this chapter, with more emphasis on adult congenital heart disease. Barbara Mulder and Folkert Meijboom joined the writing group. The second edition will be published the second half of 2009.
- The first ESC teaching course on Adult Congenital heart Disease, organized in Antalya, Turkey, November 2008, together with the AEP (European Association of Pediatric Cardiology). Organizers were Harald Kaemmerer, Pedro Trigo Trindade, Andras Szatmari, Öztekin Oto, Helmut Baumgartner.
- Since 2005, an annual 4-days teaching course on echo for congenital heart disease is organized together with the AEP and the EAE (European Association for Echocardiography). Organizers are Luc Mertens, Jan Marek and Folkert Meijboom. The 4th course is planned in Rotterdam in September.
- Since 2006, annual examination for European accreditation for echocardiography for congenital heart disease, together with AEP.
- Establishing a substantial number of sessions in the large European Congress, like the ESC annual meeting and EuroEcho.

What we are planning:

- Organize the first ESC "advanced course on Adult Congenital heart Disease" in London in April 2010.
- The teaching courses and the advanced course should become established annual or biennial events on different locations throughout Europe.
- Defining recommendations for a training program for adult congenital heart disease, to be endorsed by the ESC.
- Increase cooperation with AEP, ISACHD, CACH and North-American organizations on adult congenital heart disease about congresses, teaching courses, recommendations and guidelines.

[Back to Top](#)