President’s Message

An International Society

When we meet in New Orleans bright and early on Sunday, March 25, we shall once again have an international round table, this time discussing research in adult congenital heart disease—what’s happening, what are the challenges, where we should be going. We shall have an expanded poster presentation from active ACHD centres in different parts of the world, and hope you will take a few minutes before or after the meeting to find out how some of your colleagues have constructed their programs. We shall have an update on the International ACHD Training Opportunities project discussed at the round table last November in Chicago. And your executive committee will continue to encourage and strengthen relationships among our far-flung members and their local and regional organizations.

The ACC and the AHA have begun to play a welcome and increasing, even if overdue, role in the lives and work of ACHD specialists in the United States. Your International Society nevertheless remains the founding, unifying, core organization for ACHD caregivers worldwide, focusing on key areas where we can be most effective: promoting linkages among colleagues, facilitating information transfer, acting as a catalyst for projects and ideas, and building a place where we of the ACHD community, wherever we may live, can enrich our understanding, expand our horizons, strengthen each other by our mutual commitment, and move forward for the benefit of our special patients.

Please encourage your colleagues to join us in New Orleans, and, whether or not they can attend the meeting, encourage them to join the Society. Numbers increase our collective voice, but, even more important, the act of joining forges the connection between the individual and our shared mission.

Jack Colman, President
colman@utoronto.ca

Mission Statement

The purpose of the International Society for Adult Congenital Cardiac Disease is to promote, maintain and pursue excellence in the care of adults with congenital cardiac disease.

The Society is dedicated to the advancement of knowledge and training in medical disciplines pertinent to congenital heart disease in adults.

ISACCD Past Presidents

Gary Webb, MD ................................................................. 1994-1996
Carol Warnes, MD ............................................................ 1996-1998
Richard Liberthson, MD .................................................. 1998-2000
Daniel Murphy, Jr., MD .................................................... 2000-2002
Thomas P. Graham, Jr., MD ............................................. 2002-2004
Michael A. Gatzoulis, MD, PhD, FACC .............................. 2004-2006
ISACCD at AHA 2006: Record Attendance

The semi-annual ISACCD meeting at the Chicago Marriott Downtown on November 12, 2006, drew our largest crowd ever. At one point, there was standing room only! We began the meeting with a new feature: ACHD groups from all corners of the globe shared the details of their practice in a poster format. This format provides the opportunity for sharing problems and successes among many different groups. It was well received and we look forward to a second opportunity for this interaction in New Orleans when some of the same groups will return and new ones will be added.

Dr. Candice Silversides from the University of Toronto Heart and Pregnancy Program gave the featured address entitled: Contraception in women with congenital heart disease—an overlooked issue. She has included a summary of her talk in this edition of the newsletter.

We also had the first of our “International Round Tables” on Training in ACHD led by Dr. Curt Daniels from Columbus, Ohio. We’ll hear an update on their progress in New Orleans. Our second round table at the upcoming meeting will focus on Research.

We look forward to seeing you all in New Orleans!

Contraception in Women with ACHD — An Overlooked Issue

Candice Silversides, MD, University of Toronto Pregnancy and Heart Disease Program and the Toronto Congenital Cardiac Centre for Adults

With the increasing population of women with congenital heart disease reaching childbearing age there is an increased need for these women to have appropriate contraception counseling. Our group has recently examined this subject. We found that many women with congenital heart disease are receiving inadequate education regarding pregnancy and contraception. When women with heart disease do receive counseling, it is often from an adult congenital cardiologist.

Therefore it is important for the adult congenital cardiologist to have familiarity with these issues.

Contraception counseling should ideally begin early and should address:

1) The maternal risk of pregnancy
2) The long-term prognosis of the mother
3) The fetal/neonatal risks including the risk of transmission of congenital heart disease to the fetus
4) Safe and unsafe contraception options

Possible contraception options include:

1) barrier methods
2) combined (estrogen/progestin) oral contraceptives
3) progestin only methods
4) intrauterine devices
5) sterilization

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Highlights of ISACCD Meeting at ACC 2007

Featured Address:
Coronary Artery Anomalies of Consequence: Identification and Management
Dr Melvin Cheitlin, Professor Emeritus, University of California, San Francisco
Discussion: Dr Paolo Angelini, Texas

International Round Table Discussion on Research in Adult Congenital Heart Disease
Moderator, Dr. Michael Landzberg

Featured ACHD Centres around the World – Poster Session
Meet with colleagues and learn about the structure of their programs. Posters on display during breakfast, before and after the meeting.

Updates on ongoing ISACCD projects and innovations:
• ACHD Training Centres – Dr. Curt Daniels
• ACHD Clinics Directory – Joint project with ACHA
• IACHDN Section
• Website report
• *International Journal of Cardiology* – Dr Michael Gatzoulis

Join Us!
Sunday, March 25, 2007
7:00 - 9:00 am
Room: Balcony JK
New Orleans Marriott
555 Canal Street, New Orleans, LA
(504) 581-1000

If you are not receiving this newsletter via e-mail, please contact the society at info@isaccd.org or (919) 861-5578, so that we can update our records with your current e-mail address.
CCHA is turning 3!

The Canadian Congenital Heart Alliance (CCHA) will be celebrating its third birthday this spring! We originally banded together as a group of concerned congenital heart defect (CHD) patients stimulated by Dr Gary Webb’s call to get involved in our own healthcare. Our health was at stake, he said, and we could be our own best advocates. Until then it was a concept few of us had ever considered. We had left it to the professionals, and the “system.”

We had no idea that while the number of adult patients is now greater than ever due to excellent pediatric care, the provision of care for adults lagged far behind. We learned that care of adult patients was compromised due to a shortage of specialists trained in adult CHD, and that there were unacceptably long waiting times for surgery and other interventions, much longer than for patients with coronary heart disease! We found that incentives to attract doctors to specialize in ACHD in Canada are sorely lacking. It seemed that we were more or less invisible to hospital budget-makers, the government, the Heart and Stroke Foundation of Canada, and other potential sources of support and funding. It was news to us - and it was alarming.

In response, we joined together to help raise awareness of CHD in Canada, becoming the first Canadian CHD group to bridge the gap between pediatric and adult patients. Our mission is to improve the lives of all CHD patients—for life!

Currently we have approximately 300 members and we are on the cusp of enormous growth.

Some of our initiatives include:

- “No medical” Life, Health and Dental insurance available to members age 40 and over
- The CardiacKey—a small USB memory device which holds a patient’s clinic letter, ECG, etc. in the event of an emergency—currently in a one-year pilot project.
- Partnership with the Heart2Heart Cardiac Camp—the first teen CHD camp of its kind in Canada—which will run in Ontario and Quebec
- Representation on a special advisory panel convened by the Ontario Ministry of Health which is examining the state of care for Adult CHD in the Province of Ontario.
- Building stronger ties with the US Adult Congenital Heart Association, (ACHA) and other CHD organizations worldwide
- Recognition and participation in CHD Awareness Day on February 14
- Mentoring and “Teens in Transition” programs in conjunction with Toronto’s Hospital for Sick Children
- Participation in the annual patient conference of the Toronto Congenital Cardiac Centre for Adults.

For more information, please visit us at www.cchaonline.ca or email us at info@cchaonline.ca.
Advanced Symposium on Congenital Heart Disease in the Adult

26 & 27 September 2008
Thessaloniki - Greece
Makedonia Palace Hotel

For more information, visit: www.isaccd.org/news/FIRSTANNOUNCEMENT-ForSept08.pdf
Adult Congenital Heart Association Update

New ACHA website now available

Thanks in part to the generous support of the Medtronic Patient Link Program and Hitachi Global Storage Solutions, this fall ACHA's new website brought a number of new features, including the ACHA-ISACC clinic directory, to the ACHD community. This directory, the results of the national ACHD clinic survey spearheaded by Dr. William Davidson of Hershey Medical Center and Dr. George Warren of the ACHA Board, offers information on over 60 adult congenital heart programs in the United States and Canada. The new site also offers ACHA's personal health passport in a secure, electronic format, as well as an extensive library of new online resources.

Initial response to the improvements has been overwhelmingly positive, with rates of new membership rising ten-fold since transitioning to the new format. To visit our new site, go to www.achaheart.org.

New ACHA Strategic Initiatives Announced

The ACHA Board recently announced ACHA's new strategic objectives for 2007-2008 as follows:

1. Develop capacity to continue to grow by 50% a year through 2008.
2. Launch a comprehensive national “Don’t Get Lost” initiative.
3. Lead the establishment of a national ACHD registry
4. Expand the ACHA toolkit of services and resources to improve and extend the lives of all CHD survivors.

Developing the financial and structural resources to achieve these ambitious goals will not only require extraordinary effort on the part of the ACHA Board, staff, and Medical Advisory Board, but will also demand the help of ACHA supporters throughout the country. If you would like to volunteer to help ACHA achieve its objectives, please email Katie Freedman, Manager of Development and Events, at Kfreedman@achaheart.org.

Second National CHD Lobby A Success

Braving the ice and snow of the winter's first East Coast blizzard, 75 patients, family members, and medical professionals gathered in Washington, DC, on February 13th to push Congress to fund education and research initiatives in congenital heart disease. The attendees, representing 18 different states, first gathered the night before for a festive dinner and lobbying tip session hosted by ACHD cardiologist and White House Fellow Dr. George Ruiz. The next day, participants enjoyed breakfast hosted by the American College of Cardiology at the Capitol Hill Club, at which ACC advocacy staffer Molly Nicholson, ACHA's Legislative Committee Co-chair Disty Pearson, and ACHA President Amy Verstappen offered further training on how to make each congressional visit effective. Attendees then split into advocacy teams and collectively visited over 80 congressional offices to ask that Congress include a call for ACHD funding in the 2008 budget. ACC again generously offered travel funding for attending ACC members, and participating ACHD health care professionals included Dr. James Perry and Nicole Boramanand, APRN, of Yale School of Medicine, Dr. Michael Landzberg, Dr. Michael Singh and Disty Pearson, PA-C, of Children's...
Heart Disease and Pregnancy

Edited by

Philip J Steer, Professor of Obstetrics, Faculty of Medicine, Imperial College London and Honorary Consultant, Chelsea and Westminster Hospital

Michael A Gatzoulis, Professor of Cardiology and Congenital Heart Disease, Royal Brompton Hospital and the National Heart and Lung Institute, Imperial College London

Philip Baker, Professor of Maternal and Fetal Health, Maternal and Fetal Health Research Centre, The University of Manchester

Heart disease is the most common medical cause of maternal death in the UK and it is a major pregnancy problem around the world. The RCOG invited 26 of the world’s leading experts from the UK, Europe, the USA and Canada and Japan, to a study group in February of this year, each contributing the latest available information in this vital area.

The editors have paid great attention to accuracy but also to readability. The fact that the contributors came together to check, refine and develop their chapters and the speed with which the book has been produced have resulted in a volume which is particularly valuable for updating clinical practice in this key area.

This is a book that all obstetricians, cardiologists and anaesthetists dealing with pregnant women with heart disease should read. Anyone with an interest in women’s health care will find something for them in these pages.

Contents

1. Preconceptual counselling for women with cardiac disease
2. Contraception in women with heart disease
3. Cardiovascular changes in normal pregnancy
4. Antenatal care of women with cardiac disease: an obstetrician’s perspective
5. Antenatal care of women with cardiac disease: a cardiologist’s perspective
6. Cardiac monitoring during pregnancy
7. Cardiac drugs in pregnancy
8. Surgical and catheter intervention during pregnancy in women with heart disease
9. Antenatal diagnosis of fetal cardiac defects
10. Fetal care and surveillance in women with congenital heart disease
11. Prosthetic heart valves
12. Aortopathies, including Marfan syndrome and coarctation
13. Mitral and aortic stenosis
14. Right heart lesions
15. Pregnancy and pulmonary hypertension: new approaches to the management of a life-threatening condition
16. Cardiomyopathy
17. Ischaemic heart disease
18. Maternal cardiac arrhythmias
19. Maternal endocarditis
20. Pregnancy and cardiac disease – peripartum aspects
21. Management of the puerperium in women with heart disease
22. Impact of pregnancy on long-term outcomes in women with heart disease
23. Long-term outcome of pregnancy with heart disease
24. Consensus views arising from the 51st Study Group: Heart Disease and Pregnancy

Appendix A New York Heart Association classification of cardiovascular disease
Contraception in Women with ACHD—An Overlooked Issue
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Each method has both risks and benefits. In general, barrier methods are safe for women with heart disease, but due to high failure rates they are not recommended for women in whom the maternal risk of pregnancy is high. Combined oral contraceptives have good efficacy but are associated with a risk of both arterial and venous thrombosis. Progestin only pills are associated with less risk of thrombosis compared to combined oral contraceptives, but often have higher failure rates. Newer forms of progestin only contraception seem to be associated with lower failure rates. Intrauterine device insertion can be association with bacteremia hence risk of endocarditis. Sterilization should be considered for women in whom pregnancy carries a prohibitively high risk. Emergency contraception (combined and progestin only forms) is felt, in general, to be safe for women with congenital heart disease. Detailed reviews of contraception options in women with congenital heart disease are available. Since none of the literature examining the risks of the various methods of contraception has looked specifically at populations of women with congenital heart disease, there remain many unanswered questions, and research in the field is needed.

References

Adult Congenital Heart Association Update
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Hospital Boston/Brigham and Women’s Hospital, Dr. Marlon Rosenbaum of Columbia-Presbyterian, Dr. Dawn Calderon of Deborah Heart and Lung Center, Dr. Gary Webb, Rita Novello, RDCS, Desiree Fleck, CRNP and Deborah Shellenberger, PA-C of CHOP/HUP, Michelle J. Nickolaus, RN, of Hershey Medical Center, Dr. Wendy Book and Dr. Michael McConnell of Emory University Healthcare, Connie Nixon, RN, of the University of Florida Health System, Jenne Hickey, RN, Lindsey Cook, FNP, and Libby Sparks, CNP, of The Ohio State University Medical Center, Dr. Craig Sable of Children’s National Medical Center, Dr. Masato Takahashi of Children’s Hospital Los Angeles, Jane Sowinski, RN, of Children’s Hospital of Wisconsin, and Dr. Joseph Kay, Kathryn Richardson, RN, MSW, and Mary Brandon, RN, of The Children’s Hospital Denver. Last year’s lobbying efforts did result in a call for ACHD funding via the Senate Labor, Health, and Human Services Subcommittee—this can be viewed at www.thomas.gov. ACHA thanks all those who made this event possible, including the ACC for their on-going commitment of staff time as well support, Philips for supporting meal costs, and Actelion Pharmaceutical helping provide shuttle bus service.