

President's Message

Last March in Atlanta we engaged in an enthusiastic and encouraging discussion about future directions for our Society. When the executive board reviewed what had been discussed, and looked carefully at the mission statement drafted by our founders 15 years ago, we were happy to see that those few prescient men and women who set ISACCD in motion back in 1992 had a very good idea about what we should do and how we might do it. Those of you who looked over the mission, goals and objectives insert sent out with the dues letter in September, or who review it now on our website, www.isaccd.org, probably agree that there was a pretty good road map there, and if we continue to follow it we'll continue to do fine. We'll be discussing some specific projects for the next year or two at the meeting in Chicago in November 2006

Fortunately, some things have changed over the past 15 years, not the least being the increasing understanding in the wider cardiac community of the importance of ACHD, the needs of the ACHD population, the size of the problems they and we face, and the huge amount of gratification that can come from devoting some or all of one's career to this field. The message is getting out, and, more and more, younger members of our professions are choosing to train in ACHD and to see their future tied to this star.

We must rise to the challenge of incorporating this new blood into the tight-knit, supportive, collaborative, friendly network of ACHD aficionados that has developed since the early '90s. I have thought many times that one of the true joys of our field is the easy communication and willingness to help that is shared across institutions, cities, and international boundaries. ISACCD is a vehicle for this. We are a team! Now, we need to bring in the reinforcements.

Our nursing group is making encouraging progress. From a small nucleus a few years ago they have grown to almost 50 committed advanced practice nurses and clinical care associates who meet together and communicate regularly around mutual interests and challenges. We must work to bring medical trainees and early career ACHD docs into our group in larger numbers as well. The executive is committed to working to this end.

So... what can you do? Here are a few ideas:

- Encourage your colleagues to come out to our meetings and to join our society.
- Come to the meeting in Chicago yourself.

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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

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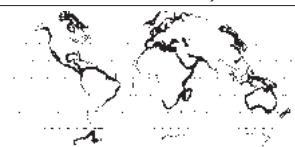
Newsletter Design/Layout

Tanya S. Henderson

Editor

Elyse Foster, MD

International Society for



Adult Congenital Cardiac Disease

ISACCD to Meet in Chicago

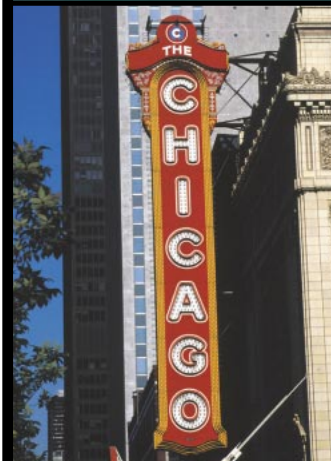
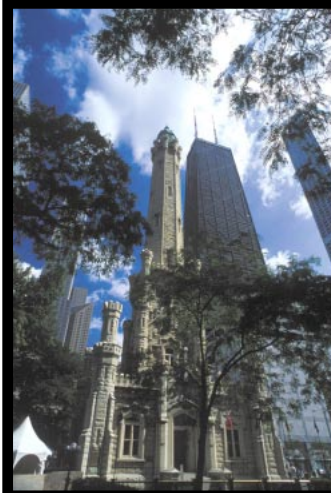
Sunday, November 12, 2006 • 7:00 - 9:00 am

Room: Los Angeles/Miami

Chicago Marriott Downtown Magnificent Mile
540 N. Michigan Ave • Chicago, IL • (312) 836-0100

Highlights of the upcoming meeting

- **Contraception in women with congenital heart disease – an overlooked issue** – Dr. Candice Silversides, University of Toronto Pregnancy and Heart Disease Program and Toronto Congenital Cardiac Centre for Adults, Toronto General Hospital, University of Toronto
- **Training in ACHD – International Round Table Discussions**
Portland, USA – Dr. Craig Broberg
Chiba, Japan – Dr. Koichiro Niwa
Belgium – Dr. Philip Moons
Montreal: McGill, Canada – Dr. Ariane Marelli
- **Featured ACHD Centres around the world** –
Posters on display during breakfast and after the meeting
New Zealand – Dr. Clare O'Donnell
Okayama, Japan – Dr. Teiji Akagi
Seattle, US – Dr. Karen Stout
- **ISACCD Business meeting**, including research report, update on ACHA-ISACCD Web Registry of ACHD Centres, and follow-up discussion of "Future Directions" for ISACCD.
- **Next ISACCD meeting:**
ACC, New Orleans, March 25, 2007
- **Other Business**



Summary of the Adult Congenital Heart Association Meeting

By Amy Verstappen

On September 15-17, the Adult Congenital Heart Association (ACHA) held its Fourth National Conference in the San Francisco Bay area, co-chaired by Daniel Murphy, MD, and Elyse Foster, MD, and hosted by Stanford University and the University of California – San Francisco.

The event included three parallel tracks: the first ACHA ACHD Research Symposium, ACHA's Patient/Family Conference, and a CME course for medical professionals with an interest in ACHD. 291 attendees and 62 faculty and researchers were in attendance, including 240 patients and family members living with congenital heart disease. Faculty consisted of members of ACHA's Medical Advisory Board, as well as additional ACHD experts from throughout the country, and the program addressed a wide array of topics relevant to the ACHD survivor. Notable program additions were an afternoon devoted to psychosocial issues led by national leaders in ACHD psychology, presentations on disability law, and multiple sessions led by patient-presenters on areas of expertise such as electronic health records, living with cyanosis, and preparing for open-heart surgery. In addition to attending case-based presentations, CME attendees joined with patients, families, and research attendees to hear five CHD survivors share their moving, insightful, and often humorous perspectives on living with congenital heart disease.

The same upbeat attitude was maintained at the Gala dinner, at which Keynote Speaker Joseph Perloff, MD, offered historical observations and ACHD humorist Rudy Wilson Galdonik shared her "Top Ten Reasons Why it is Good to Have a Congenital Heart Defect." Patients and family members also joined the researchers and medical professionals at the Research Symposium's moderated poster sessions, and attendees widely commented that this combination of participants and points of view made the event truly unique. With generous assistance from Hitachi Global Storage Technology and the Karen McNulty Memorial Scholarship Fund, ACHA was pleased to offer over \$30,000 in travel, hotel, and registration assistance to low income/disabled attendees. Additional conference support was provided, in part, by Actelion Pharmaceuticals, AGA, the American College of Cardiology, ISACCD, and the AHA Councils of Cardiovascular Disease in the Young and Clinical Cardiology. Excerpts from one attendee's comments are below:

If you didn't go this year... start saving NOW for the next one... This conference will change your life! ...The conference gave us a chance to network with cardiologists, surgeons, electrophysiologists, psychologists, social workers, other patients, all people we don't generally have access to in our "real lives." We learned about the electronics of the heart and why arrhythmias happen and what to do when they happen. We learned what's in the future surgically and in the future of cath. We learned about insurance companies, how to work through them. We learned about disability law. We learned about the history of Congenital Heart Disease and the people who made it possible for children with CHD to become adults... We learned that there are a lot of other people out there going through the same confusion, frustration and emotional struggle that we are... We found humor in our situation!!! We grieved for those who couldn't be with us... I learned that I don't have so much to fear... That there are people who understand these conditions and that they will help us and lead us through whatever we face. I learned that we aren't alone. I learned that I have a support group of people that I didn't know existed. And I look forward to learning more!

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.

Update on Project Committee

Dr. William Davidson

In 2006, ISACCD's project committee, working with the Adult Congenital Heart Association, determined to establish the manpower resources available for care for adults with congenital heart disease (ACHD) in the US and Canada. Surveys were sent to every medical and pediatric cardiology training program, to all major medical centers in the United States and Canada and to all ISACCD members and known ACHD programs. Over 200 surveys were sent out. So far 60 programs have been identified. As of May, when this information was submitted to the AHA's Annual Scientific Session, 55 programs with a median size of 450 patients (range 100 to 2,500 patients) had been identified throughout the United States. The number of programs has grown exponentially since the founding of the UCLA Program in 1978. One-third of the programs that exist today have only been in existence since the year 2000. Older programs tend to be larger. Ten Canadian centers identified were larger Canadian sites range from 240 to 6,550 patients in size. In the United States 5% of ACHD patients are followed in an ACHD site, approximately 10% of Canadian ACHD patients are seen in Canadian sites. Information was also obtained from the Royal Brompton in London which follows approximately 5,000 patients. Information ascertained included type and size of hospital, number and type of physicians following ACHD patients, number of years of a program's existence, existence and use of a transition program, number and type of mid-level practitioners, availability of ACHD experienced imaging and interventional capabilities, surgical resources, and availability of support services. A manuscript is in the works. Information on American programs will be presented Tuesday afternoon at the American Heart Association in November.

Current Status in Adult CHD in East Asia

Koichiro Niwa, Chiba Cardiovascular Center, Ichihara, Japan

In East Asian countries, facilities in adult CHD have been established in some institutions in Korea and Japan. However, there are no established institutions of such kind in other areas in East Asia. In Japan, the number of adults with CHD is currently estimated at 400,000 with approximately 9,800 CHD patients with CHD reaching adulthood every year. Specialized care facilities for adults with CHD in Japan and Korea have been establishing since late 1990s. The Japanese Society for Adult CHD (JSACHD, 1998, current president; Koichiro Niwa MD) and Korean GUCH society (2001, president Heung Jae Lee MD) were established and became active with a close collaboration.

The membership of the JSACHD is rapidly growing (154 members in 1998 and 585 in 2006). The membership includes pediatric cardiologists (59%), CV surgeons (18%), adult cardiologists (15%), as well as several obstetricians and other interested parties. The 8th annual meeting was held in January 2006. This was a two-day meeting which included a symposium and free papers, with four invited speakers from foreign countries and over 10 Korean members. Free papers and attendants of the Society meeting have also been growing (25 to 59 papers in 2006, 154 in 1998, and 214 in 2006). The JSACHD has had a Web Page (www.jsachd.com) since 2001. Guidelines for care of the Adult with Congenital Heart Disease were published by a committee appointed by the Japanese Circulation Society and revised in 2006.

Further growth of this population can be anticipated in Asian countries similar to that observed in North America and Europe. However, a multidisciplinary team approach that includes adult cardiac and non-cardiac disciplines, obstetricians, and anesthesiologists has not yet been established in most Asian facilities. Mainly pediatric cardiologists continue to provide special care for adults with CHD. Formal education and training systems for Adult CHD by Cardiology Society are still lacking. However, 15% of the current members in JSACHD are adult cardiologists, a number that is promising for future establishment of team approach. A patient organization for Adults with CHD was established in Japan in the early 1990s.

As the care for adults with CHD becomes increasingly complex, the problems we are facing in establishing adequate facilities are similar to those in North America and Europe. Therefore, it is timely for ISACCD to work closely with European GUCH and Asian Adult CHD Society.

ISACCD Spring Meeting presentation

In March, at ISACCD's spring meeting, Dr. Michael McConnell gave a presentation on the Emory/Sibley Adult Congenital Cardiac Program. He was kind enough to summarize his presentation:

"The Emory/Sibley Adult Congenital Cardiac Program began in the fall of 2000, as a collaborative effort between an Internal Medicine Cardiologist (Dr. Wendy Book) and a Pediatric Cardiologist (Dr. Michael McConnell). Adult congenital patients had previously been seen at Emory Hospital by Dr. Robert Franch, an internal medicine cardiologist who practiced at Emory from 1956-2001. Dr. Franch performed the first balloon atrial septostomy in Atlanta in the 1960s, and took care of many patients, both pediatric and adult who had congenital heart disease. He also helped direct the Crippled Children's Clinic, where many Georgia patients with congenital heart disease were followed throughout their lives.

The initial Emory/Sibley Adult Congenital Clinic met 1/2 day a month, but within 18 months, the clinic was meeting one full day each week. Realizing that additional resources were necessary, we arranged a site visit from Dr. Dan Murphy. During his site visit, Dr. Murphy spoke with both the pediatric and adult thoracic surgeons, anesthesiologists at both the Children's Hospital and Emory, as well as cardiologists, hospital administrators, the Chief Medical Officer of Emory Healthcare, as well as the Chief Financial Officer. At the end of his two-day visit, Dr. Murphy summarized the Emory/Sibley Adult Program in this way: "Because of its geographic location, and the size and area of influence of the Sibley Heart Center, Emory probably has a better chance of developing a world-class, internationally respected, ACHD program than any other location in the U.S." Dr. Murphy's statement was based on many factors, including the fact that Atlanta has 4.4 million people, 1.5% of the United States population. The Atlanta population is expected to grow to 5.2 million people by the year 2010. Atlanta is also expected to grow by over 200,000 children in the next five years. That is more children than currently live in either of the states of South Carolina or Alabama. Of course, Atlanta boasts the busiest airport in the world, and this facilitates access to healthcare from virtually anywhere in the world.

Emory and the Sibley Heart Center have a collaborative relationship where patients can be seen at the medical system that suits their needs best. The "adult hospital" (Emory) and the children's hospital (Egleston) are connected by a tunnel, and most physicians have staff privileges at both hospitals. The Pediatric Cardiology Program is quite large, and currently included 32 pediatric cardiologists. Children's Healthcare of Atlanta was ranked in the top 10 children's hospital in the country, and the Sibley Heart Center was ranked in the top five by Child Health Magazine in both 2004 and 2005. The Pediatric Cardiothoracic Surgery Program is quite busy, and in 2005 performed 914 cases (572 open heart).

The Emory/Sibley Adults Congenital Clinic now meets twice a week, and averages almost 100 visits per month. We also average approximately 15 new patients each month. In the year 2005, we sent 43 patients for surgery, compared to 31 in 2004. In a separate 24 month period, 62 patients had pulmonary valve replacements at Emory University Hospital.

The explosive growth of the program has resulted in 103 patients with systemic right ventricles who are now cared for at the Emory/Sibley Adult Congenital Cardiac Program. We also have 42 patients with congenital heart disease and pulmonary vascular disease on therapy, including endothelin antagonists, prostacyclins, and sildinafil.

The downstream financial effect for the Emory Hospital system has been positive. We have had 146 hospital admissions, and 41 electrophysiologic studies performed in the year 2005.

The Program has been able to contribute to the literature about adults with congenital heart disease, including reports published about bosentan therapy in patients with Eisenmenger's syn-

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Congratulations

Gary Webb of Canada, now in Philadelphia, and Joseph Perloff of Los Angeles, both North American-based founding members of ISACCD, have been honored for their contribution to ACHD by being declared Honorary Members of the Working Group on Grown-Up Congenital Heart Disease of the European Society of Cardiology. Their appointment was announced at the recent meeting of the Working Group in Barcelona during the World Congress of Cardiology in September 2006.

Inaugural ACHD Research Conference parallels the 4th National ACHA Conference

On September 15th and 16th, the first National ACHA Research Symposium was held in San Francisco. The organization received support from the NHLBI through a grant submitted by Amy Verstappen and Dr. Elyse Foster with the assistance of Dr. Karen Kuehl. The major focus of the conference was on two critical issues in adult congenital heart disease:

- 1) The evaluation of right ventricular shape and function, and
- 2) Issues related to pregnancy and reproduction.

Drs. Elyse Foster and Gary Webb co-chaired the conference. It began with a moderated poster session with five excellent abstracts on a broad range of topics. A research dinner followed the faculty reception. The keynote speaker was Dr. Stephen Lazarus, Professor of Medicine, Pulmonary

Division, UCSE. The title of his talk was: Multicenter Clinical Trials: Lessons from the Lung Community. He shared with us the mechanism for obtaining research through the NHLBI for research networks. Dr. Welton Gersony, who was in attendance, discussed the currently funded Congenital Heart Disease network. Based on the presentation, a working group will be established with the aim of lobbying interested parties at the NHLBI to consider issuing an RFA to solicit centers interested in participating in a research network.

The second day of the symposium began with a superb and comprehensive presentation by Dr. David Sahn, entitled: Right Ventricular Function: Assessment with Novel Imaging Methods. Throughout the day, several working groups convened to discuss the following topics: Right ventricular function (David Sahn), Psychosocial Issues (Arwa Saidi), Pregnancy and reproduction (Carole Warnes). A group of young investigators also had the opportunity to convene. This group, led by Drs. Michael Landzberg and Gary Webb, has been meeting over the past year to develop multicenter protocols. A second moderated poster session was well-attended by researchers, patients and providers.

Finally, we concluded with a wrap-up session to present the ideas generated by the various working groups. A list of the abstracts and their authors are appended (next page). Ten travel grants were awarded to the young investigators who had their abstract accepted for presentation.

In addition to the Research Symposium, Daniel Murphy, MD, and Elyse Foster, MD, co-chaired a one-day CME program entitled: Problem Solving in Adult Congenital Heart Disease. A broad range of topics was presented by nationally recognized speakers. The case-based approach stimulated much discussion and was well-received by the attendees.

In all, there were almost 300 attendees that included patients and their family members, researchers and community and academic physicians interested in congenital heart disease. Please see the accompanying article (on page 3 of this newsletter) by Amy Verstappen reporting on the Patient/Family Conference. The enthusiasm and interest in Adult Congenital Heart Disease was palpable during all three days of the conference. On the final day, Elyse Foster summarized all of the research for patients and family members in attendance. Their appreciation and interest for the research presented was truly apparent in their questions and comments.

We look forward to the 5th National ACHA conference returning to the East Coast in 2008!!



Dan Murphy and Elyse Foster, co-chairs of the ACHA National Conference in San Francisco, September 15 - 17, 2006, with Dr. Joseph Perloff, who was honored at the Gala Dinner, for his contributions to the field of Adult Congenital Heart Disease.

List of Presented Abstracts:

Adult Patients with Eisenmenger Syndrome Report Flying Safely on Commercial Airlines.

Craig S. Broberg, MD Anselm Uebing, MD Linda Cuomo, MD Swee Thein, MD, Michael G. Papadopoulos, MD Michael A. Gatzoulis, MD, PhD, FACC, Oregon Health and Science University and the Royal Brompton and Harefield NHS Trust

Pregnancy Outcomes in Women with Congenital Heart Disease

Paul Khairy, MD, PhD; David W. Ouyang, MD; Susan M. Fernandes, MPH, PA-C; Aviva Lee-Parritz, MD; Katherine E. Economy, MD; Michael J. Landzberg, MD, Boston Adult Congenital Heart (BACH) and Pulmonary Hypertension Program, Boston, MA.

Measuring Right Ventricular Volume in Tetralogy of Fallot

Florence Sheehan, MD, University of Washington

Synthetic Oligonucleotide Multiplex Ligation-dependent Probe Amplification (MLPA) for the Detection of Novel Deletions in Candidate Genes Causing Tetralogy of Fallot

Jennifer C. Lin, Steven C. Greenway, Roger E. Breitbart, Jessie R. Hastings, Alexandra Pereira, Christine E. Seidman, J. G. Seidman
Seidman Laboratory, Harvard Medical School, Boston MA

The Psychological Adjustment of Adults with Congenital Heart Disease

Adrienne H. Kovacs, Emily A. Kuhl, Connie Nixon, Samuel F. Sears, and Arwa Saidi.
University of Florida (Departments of Pediatrics and Clinical and Health Psychology), Gainesville, Florida

Evaluation of Complex Adult Congenital Heart Disease with Cardiac Computed Tomography

Alexander R. Opotowsky MD, MPH, Gary D. Webb, MD, and Harold I. Litt MD, PhD
Hospital of the University of Pennsylvania, Philadelphia, PA

Outcomes of Late Transition Among Adults with Transposition of the Great Arteries

Priya Pillutla, MD; Valerie Bosco, NP; Nelson B. Schiller, MD, FACC, Elyse Foster, MD, FACC
University of California, San Francisco

Treating Obstructive Sleep Apnea in Patients with Complex Congenital Heart Disease Following the Fontan Repair

Karen Stout, Nathaniel F. Watson, Theodore Bushnell, Mary E. Schlater, Michelle Gurvitz, Thomas K. Jones, University of Washington

Morbidity and Mortality among Adult Congenital Heart Disease Patients in Manitoba, Canada

M. Mendelson*, T. Gosal†, and J.W. Tam†

*Department of Pediatrics, McGill University, Montreal, Canada.

†Section of Cardiology, University of Manitoba, Winnipeg, Canada.

Myocardial Fibrosis Patterns Correlate with Adverse Right Ventricular Morphology and Function in Patients with Repaired Congenital Heart Defects

Anne Marie Valente, MD*, Salim F. Idriss, MD, PhD, Peter Cawley, MD, John Heitner, MD, Igor Klem, MD, Joseph Kay, MD, Michele Parker, RN, J. René Herlong, MD, J. Kevin Harrison, MD, Raymond Kim, MD.

* Boston Adult Congenital Heart (BACH) and Pulmonary Hypertension Program, Boston, MA, & Duke University Medical Center, Durham, NC.

ISACCD Spring Meeting presentation

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drome, myocardial infarctions in adolescents, B natriuretic peptide levels in adults with congenital heart disease, and the effects of pulmonary valve replacement in patients with tetralogy of Fallot.

In the future, we hope to participate in fellowship training, gain additional staff so that we can expand to daily clinics, and have a separate inpatient service at Emory Hospital. Of course, we hope to improve our research portfolio, and add to the growing body of knowledge concerning adults with congenital heart disease.”

*Michael E. McConnell,
MD, FAAP, FACC,
Sibley Heart Center
Cardiology*

*Submitted by:
Elyse Foster*

President's Message

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- Bring a colleague, especially a younger colleague, who will enjoy the breakfast, the camaraderie, the education, and the opportunity to link with others with shared interests and passion.
- Bring your issues; we need to hear from you so we can organize to support your needs.
- Bring your desire for enlightenment; the educational program is focused on issues important to us as ACHD practitioners
- Bring your expertise; share with colleagues who have similar goals.
- Bring your energy and your commitment; our organization needs you.

Jack Colman, President
j.colman@utoronto.ca

Save the Date Philly ACHD

17th Annual Congenital Heart Disease in the Adult

May 30 - June 2, 2007

The Union League
Philadelphia, Pa.

www.chop.edu/cme

New City
New Topics
New Speakers
Abstract Competition



*For pediatric and adult cardiovascular specialists,
cardiovascular surgeons, specialists in cardiac imaging,
internal medicine specialists, nurse clinicians and nurse practitioners*



Philadelphia Adult
Congenital Heart Center



The Cardiac Center at
The Children's Hospital of Philadelphia