

President's Message

By Thomas P. Graham, Jr., M.D.

It is a great pleasure and an honor to be the 5th President of the ISACCD. We owe a great debt of gratitude to Drs. Webb, Warnes, Liberthson and Murphy for their leadership in the promotion and advancement of our mutual purpose: to promote, to maintain and to pursue excellence in the care of adults with congenital heart disease.

There are a number of exciting developments in our subspecialty and I want to invite all of you to attend our next meeting on Sunday, November 17, 2002 at 7:00 a.m. at the Congress Plaza Hotel in Chicago. Details are inside the newsletter for the time, place and agenda.

At the meeting, we will plan to have a very informative presentation and discussion about the ISACCD registry/database to which many of you contributed a number of years ago. Dr. Ariane Marelli will be presenting data at our meeting as well as presenting two posters at the AHA meeting. This will be an important time to discuss both these data and the possibility of continuation of this type of activity by the society.

The Web site is now up and running and continues to grow. Many thanks to Dr. Murphy, Dr. Bashore and Susan Nunn for their efforts. If you have not seen the Web site, please do so that you can give us feed back at the meeting in Chicago or by e-mail. It is quite easy to find a referring physician from the web site when patients move to a new location.

In addition, there is extremely useful patient information on the Web site regarding both simple and complex congenital heart disease problems in adults. There is also a nice link to the AHA/CVDY Web site with good adult CHD information and color diagrams of various lesions that I have found useful in sharing with patients.

We will be discussing the possibility of an official journal for ISACCD at our Chicago meeting. Dr. Gatzoulis has been involved with contacts at two excellent journals and will present a report regarding these future plans.

There have been very interesting developments from the project committee. Dr. Elyse Foster has completed the first draft of the multi-institutional report on adult patients with the Fontan procedure. This manuscript should be finished by the end of the year and hopefully accepted by one of our prestigious journals.

We have completed data entry for the pulmonary valve replacement study and have 93 patients from 7 institutions. An abstract is being sent to the ACC.

Drs. Murphy and Gatzoulis continue to be active in developing the Futura Monograph Series. The tetralogy monograph was a success and there will be a symposium at the AHA on atrial septal defect which will form the basis for a second monograph. There are plans for a third monograph possibly on Marfan syndrome, and we will need your input at the meeting in Chicago regarding the future of this very successful endeavor.

Please let us know about what you would like to see at future meetings. We look forward to seeing you in Chicago.

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.



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ISACCD Spring Meeting Highlights

By Elyse Foster, MD

At the March meeting of the International Society of Adult Congenital Cardiac Disease, we were honored to have Dr. Martin Rosas of the National Institute of Cardiology of Mexico in Mexico City, Mexico as our speaker. The institute was created in 1944 by Dr. Ignacio Chávez Sánchez. He and his colleagues achieved international recognition for their scientific and clinical excellence. In 1950, the department of pediatric cardiology was started by Drs. Jorge Soberon, Espino Vela and Maria Victoria de la Cruz.

Dr. Fause Attie brought the era of modern cardiology to the institute in 1987 when he became chief of pediatric cardiology. The National Institute of Cardiology of Mexico now has 200 beds, 50 of them dedicated to congenital cardiac disease. In addition to an inpatient service of 15 beds, an outpatient service in adult congenital heart disease has now been established, which serves 80 to 120 patients each week. In addition to Drs. Rosas and Attie, Drs. Carlos Zabal and Alfonso Buendia see patients on the adult congenital service. Collaborative relationships with Psychiatry and Genetics have been established. They provide electrophysiology and interventional cardiology services.

Dr. Rosas reported the results of their recently published randomized trial comparing medical to surgical therapy for secundum atrial septal defect in patients aged over 40 years. Surgical closure of secundum atrial septal defect in adults

aged over 40 years remained controversial due to a lack of data from controlled trials.

They recruited 521 patients with secundum atrial septal defect aged over 40 years referred for treatment, 48 were excluded. The remaining 473 patients were randomly assigned to surgical closure (n=232) or medical treatment (n=241). The primary end point was a composite of major cardiovascular events (death, pulmonary embolism, major arrhythmic event, embolic cerebrovascular event, recurrent pulmonary infection, functional class deterioration, or heart failure). Overall mortality was the secondary endpoint. Analysis was by intention to treat. Prognostic indicators were measured.

The results were as follows. The median follow-up was 7.3 years (range 2 – 13 yr). The risk of meeting the primary end point was significantly higher in the medical group, with a univariate hazard ratio of 1.99 (95% CI, 1.23 – 3.22) and a multivariate hazard ratio of 1.85 (95% CI, 1.08 – 3.17). Although the survival analysis did not reveal differences between surgical and medical treatments in overall mortality (hazard ratio of 1.71; 95%CI, 0.76 – 3.86), the multivariate analysis adjusted by age at entry, mean pulmonary arterial pressure and cardiac index, demonstrated significant differences between the study groups (hazard ratio of 4.09; 95% CI, 1.41 – 11.89).

The authors concluded that surgical closure was superior to medical treatment in improv-

ing both the composite of major cardiovascular events in patients with secundum atrial septal defect aged over 40 years. When examining the individual components of the composite endpoint, there was a significant difference in the incidence of pneumonia in the surgical group compared to the medically treated patients. The incidence of all other cardiovascular events was similar. The outcome was related to the mean pulmonary arterial pressure, age at diagnosis, and cardiac index. Because of the higher risk of morbidity and mortality, they recommend that anatomical closure should always be attempted as the initial treatment for atrial septal defect in adults aged over 40 years with pulmonary arterial systolic pressure less than 70 mmHg, and Qp/Qs over 1.7. Surgery must be performed as soon as possible, even if the symptoms or the hemodynamic impact seem to be minimal. The results of percutaneous device of closure of atrial septal defect need to be compared to surgical closure.

Dr. Rosas also reported the Institute's experience from 1972 to 1997 with 72 unoperated adult patients over the age of 25 years with Ebstein's anomaly. They studied the patterns of presentation, anatomic characteristics, outcome, and predictive factors for survival with a follow-up period 1.6 to 22.0 years. Patients were classified in three groups of severity according to the echocardiographic appearance of the septal leaflet attachment

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San Francisco Cardiologists Form Regional Society for Adult Congenital Heart Disease

Cardiologists in the San Francisco Bay Area interested in adult congenital heart disease have recently formed the Bay Area Adult Congenital Heart Disease Society. The society began meeting in 2001 in order to share difficult cases and to advocate the needs of patients in Northern California. Members include adult and pediatric cardiologists and cardiovascular surgeons. There is a part-time executive director.

The difficulties posed by transition into adulthood are not unique to patients with congenital heart disease but are also experienced by those with other chronic illnesses such as cystic fibrosis and

muscular dystrophy. Members of the society have provided input from the cardiologist's perspective to a California state task force making policy recommendations to transition the medical care of teenagers with these chronic diseases into adulthood.

The group meets quarterly, rotating through regional institutions like California Pacific Medical Center, Alta Bates Hospital, Stanford and UC San Francisco to discuss complex patients with management dilemmas. These meetings are attended by 30-40 providers including specialists in EPS, heart failure, pulmonary hypertension, as well as affiliated

specialties (OB/GYN, neurology) and have been very productive. Four to five patients are presented during a two hour evening meeting.

There has also been increasing involvement of the fellowship programs in the area, and a database is being developed that will be available to physicians in Northern California.

The steering committee consists of Drs. Elyse Foster, Daniel Murphy, Pate Thompson and Robert Popper. For details feel free to contact Peggy Powers at 415-923-3002 or PowersP@sutterhealth.org.

ISACCD Spring Meeting Highlights

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of tricuspid valve. The mean age at diagnosis was 23.9 ± 10.4 years, and the most common clinical presentation was an arrhythmic event (51.4%). There were 30 (42%) deaths, including 6 from arrhythmia, 12 related to heart failure, 7 sudden, 2 unrelated, and 3 unascertained. According to Cox regression analysis, predictors of cardiac-related death included age at diagnosis (hazard ratio 0.89 for each year of age, 95% confidence intervals [CI] 0.84-0.94), male sex (3.93, 95% CI, 1.50-10.29), degree of echocardiographic severity (3.34, 95% CI, 1.78-6.24), and cardiothoracic ratio > 0.65 (3.57, 95% CI, 1.15-11.03). During follow-up,

morbidity was mainly related to arrhythmia and refractory late hemodynamic deterioration. The magnitude of tricuspid regurgitation, cyanosis; and the New York Heart Association (NYHA) functional class at time zero were significant risk factors by univariate analysis, but not after multivariable analysis.

The investigators concluded that the pattern of presentation, clinical course, and prognosis of unoperated adult patients with Ebstein's anomaly are influenced by as cardiothoracic ratio, sex, age at diagnosis, and the echocardiographic features. Initial symptoms are usually mild, commonly related to

supraventricular arrhythmias, and are not associated with the long-term outcome. The severity of the pathology was the main determinant of survival only in extreme cases, but not in those with mild or moderate deformations, which are more common in adults. Adult patients with Ebstein's anomaly should not be considered as a simple low-risk group.

In summary, we were fortunate to learn about the extensive experience in Adult Congenital Cardiac Disease and the superb clinical investigation by the world-renowned the National Institute of Cardiology of Mexico.

Agenda for ISACCD Meeting

November 17, 2002 • Congress Plaza Hotel • Chicago, IL

1. Welcome/Introduction - Dr. Graham
2. Report from ISACCD Registry/Database - Dr. Ariane Marelli
3. Discussion Regarding Further Development of a Registry/Database - Dr. Graham
4. Experience of the Adult CHD Program and the Royal Brompton Hospital, London - Dr. Michael Gatzoulis
5. Executive Committee Report - Dr. Graham
6. Official Journal for ISACCD - Dr. Gatzoulis
7. Membership Report - Dr. Graham
8. Newsletter Report - Dr. Elyse Foster
9. Web Site Report - Dr. Graham
10. Project Committee Report - Dr. William Davidson
11. Futura Monographs - Tetralogy, ASD, Marfan Syndrome - Dr. Murphy
12. GUCH Relationship/ Joint European Meetings - Dr. Gatzoulis
13. Next Meeting - ACC, 3/30/03
14. Other Business
15. Adjourn

Future Meetings

June 5-7, 2003

The 14th Annual International Symposium on Congenital Heart Disease in the Adult
Toronto, ON, Canada

Course Directors:
Drs. David J. Sahn, Peter P. Liu, and Gary D. Webb

For more information contact:
Dr. Gary Webb on
Gary.Webb@uhn.on.ca

Aug. 31- Sept. 3, 2003

European Society of Cardiology Annual Meeting
Vienna, Austria

For more information visit:
<http://www.escardio.org/>



The Fourth World Congress of Pediatric Cardiology & Cardiac Surgery

September 18 - 22, 2005
Buenos Aires, Argentina

CHAIRMEN: Horacio Capelli, M.D.-Guillermo Kreutzer, M.D.

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Sept. 19-20, 2003

The 2nd Joint European/ North American Symposium on Congenital Heart Disease in the Adult — In Honor of Professor Joseph K. Perloff, MD
Santorini, Greece

Course Directors:
Drs. Michael A. Gatzoulis, George Sarris, Darryl F. Shore and Gary D. Webb

For more information contact:
Dr. Michael Gatzoulis on
m.gatzoulis@rbh.nthames.nhs.uk

ISACCD to Meet in Chicago

Sunday, November 17, 2002

7:00-9:00 am

Congress Plaza Hotel Chicago, Illinois

The semi-annual meeting of the International Society for Adult Congenital Cardiac Disease (ISACCD) is scheduled to be held during the Annual Scientific Sessions of the American Heart Association in Chicago, IL. The ISACCD meeting will take place Sunday, November 17, 2002 at the Congress Plaza Hotel in the Grant Park Room.

All are encouraged to attend! We look forward to seeing you in Chicago.

If you will be attending the meeting, return this form by November 8, 2002 by mail, fax or e-mail.

Yes, I will attend the semi-annual meeting of the ISACCD November 17, 2002 in Chicago, IL.

Name _____

Affiliation _____

Address _____

City _____ State _____ Zip _____

Phone _____

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Send registration to:

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Please RSVP by November 8, 2002!

