

President's Message

by Thomas P. Graham, Jr., MD

Broadening our Base

Our current membership stands at 219, comprised of 194 cardiologists and cardiovascular surgeons, 15 trainees and 10 allied health professionals. We are anxious to broaden our base of membership in an effort that we believe will best service our growing population of patients.

It is the hope of the current executive board that recent initiatives will help to promote membership in our society. We have established a relationship with the *International Journal of Cardiology*, which will now serve as the official journal of ISACCD. This will provide a venue for the publication of important articles related to our growing field. The journal is available online, and a subscription will be offered to members at a substantial discount. Dr. Michael Gatzoulis has agreed to serve

as the first Associate Editor for the section of the *IJC* devoted to Adult Congenital Heart Disease.

Under the leadership of Dr. Mary Etta King and Dr. Ariane Marelli, data compiled from the original database has now been presented to the American Heart Association. Several manuscripts have been submitted for publication. Drs. Marelli and King are working to put together a second phase of the database.

The research committee continues under the guidance of Dr. William Davidson. The Fontan manuscript by Dr. Elyse Foster and the pulmonary homograft manuscript by Dr. Thomas Graham are in revision and will soon be submitted.

With a growing patient base and shrinking health care

dollars, we have a need to expand in the political arena. We are at a critically important juncture with the publication of the Bethesda Conference Proceedings and must regain momentum that will enable us to be the best possible advocates for our patients. Since there is strength in numbers, a larger society will carry greater weight.

Our challenge to each member is to convince at least one of your colleagues to join ISACCD in 2003. Have them write your name on their membership application. We will recognize and award a free *IJC* subscription to the current member who refers the greatest number of new members.

Help us broaden our base in 2003!!!

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.

Dear ISACCD Member:

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

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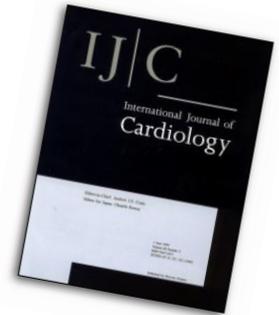
Elyse Foster, MD

New Affiliation: ISACCD and International Journal of Cardiology

by Michael Gatzoulis, Associate Editor, First term

The *International Journal of Cardiology (IJC)* has been voted unanimously as the affiliated journal for our society. The move follows a recent search by the ISACCD executive committee and a discussion at last November's semi-annual Meeting in Chicago. The decision was based on the international nature and readership of the *IJC* which, with its worldwide distribution, complements the aims of our society. The current Editor in Chief, Professor Andrew JS Coats, and the publishers ELSEVIER welcome this collaboration. The journal can be accessed in its full electronic form via Cardiosource. The ISACCD executive committee has secured free electronic access for all ISACCD members for a

period of 12 months, with optional joint membership to follow thereafter. In addition, a single page/per issue (there are 15 *IJC* issues per year) will be allocated free of charge for ISACCD activities, announcements, news, future meetings etc. The *IJC* is available on Medline and has doubled its impact factor over the last three years (current impact factor 1.164, at the upper 50% of the Cardiology sector journals). This is an exciting development for both ISACCD and *IJC* with the potential for mutual growth and benefit. It provides additional publishing space for our work, exposes the society and the adult congenital heart field to a new cardiological audience and may facilitate increase in our membership.



Consider submitting to *IJC* your original papers and letters (including interesting case reports and images in cardiology) and also helping with editorials and hot topic reviews. Submissions and reviews are all electronic and *IJC* now has a reputation for a fast response. More ISACCD members will be invited to join the *IJC* international editorial board and participate in/contribute to the review process.

ACHD Courses

September 19-20, 2003

The 2nd Joint European/North American Symposium on Congenital Heart Disease in the Adult – In Honour 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 please visit: www.rbh.nthames.nhs.uk or contact: Beverley Charters, BCOS Ltd., P.O. Box 20710, London E3 5UE, UK; Tel: +44 (0) 20 8980 0679; Fax: +44 (0) 20 8980 0725; E-mail: BCharters@bcos.demon.co.uk; and Dr. Michael Gatzoulis at m.gatzoulis@rbh.nthames.nhs.uk.

September 27-29, 2004

The 3rd Joint European/North American Symposium on Congenital Heart Disease in the Adult – At The Royal College of Surgeons of England, London, UK

Course Directors: Drs. Michael A. Gatzoulis, David Sahn and Darryl F. Shore.

For more information please visit: www.rbh.nthames.nhs.uk or contact: Beverley Charters, BCOS Ltd., P.O. Box 20710, London E3 5UE, UK; Tel: +44 (0) 20 8980 0679; Fax: +44 (0) 20 8980 0725; E-mail: BCharters@bcos.demon.co.uk; and Dr. Michael Gatzoulis at m.gatzoulis@rbh.nthames.nhs.uk

The Adult Congenital Heart Disease Program at the Royal Brompton Hospital

by Elyse Foster, MD

Dr. Michael Gatzoulis presented the experience at the Royal Brompton Hospital in ACHD at the ISACCD meeting in November 2002.

The congenital heart disease service at the Royal Brompton Hospital has an illustrious history beginning in the 1950s under the direction of Dr. Paul Wood and Lord Brock. The pediatric service was established and in the 1970s was led by Drs. Graham Miller, Elliot Shinebourne and Chris Lincoln. Dr. Robert Anderson, the preeminent cardiac pathologist, joined the team at that time. Dr. Jane Somerville established the GUCH, or Grown-Up Congenital Heart Disease Unit in 1975 at the National Heart Hospital. Her incredible foresight led to a major new discipline in cardiology. She recognized that the children who were surviving with their congenital heart disease would require ongoing specialized care that could not be provided by most

cardiologists caring for adults. The Unit moved to the Royal Brompton in 1989.

Following Dr. Somerville's retirement in 1999, Dr. Michael Gatzoulis has led the distinguished team at the Royal Brompton. In addition to another full-time ACHD cardiologist, there are two congenital heart surgeons and one staff echocardiographer. They work closely with the two pediatric and two fetal cardiologists.

They currently care for more than 5,000 patients and have a dedicated eight-bed inpatient service. There are monthly obstetrical clinics and weekly pulmonary hypertension clinics, in addition to weekly ACHD clinics. An important feature of their practice is the quarterly transition clinic, which they run in cooperation with their pediatric colleagues.

They serve as an important and nationally recognized

training team. Along with Dr. Gary Webb of the University of Toronto, Dr. Gatzoulis has established the prestigious joint fellowship program, where the first year is spent at the Royal Brompton and the second in Toronto. The Royal Brompton team is currently applying for funding for a regional training center in congenital heart disease.

Fellows are actively involved in research related to adult congenital heart disease. There are several active projects underway. The team is actively studying the effects and timing of late interventions on ventricular function. Research is continuing on mechano-electric interactions and their impact on arrhythmias and sudden death. Finally, there has been increasing interest in studying the mechanisms of heart failure in congenital heart disease.

The 14th Annual International Symposium on Congenital Heart Disease in the Adult

June 5-7, 2003
Toronto, ON, Canada

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

For more information, see the meeting program at <http://www.isaccd.org/news/torontoprogram2003-1628.pdf> or contact: Dr. Gary Webb at gary.webb@uhn.on.ca



Mark your calendar!

The Ahmanson-UCLA Adult Congenital Heart Disease Center will hold its annual program: "Adult Survivors of Congenital Heart Disease: A tribute to the first 50 years of cardiac surgery" on Saturday April 26, 2003, in Marina del Rey, California.

For information contact: Office of Continuing Medical Education, David Geffen School of Medicine at UCLA (310) 794-2620; fax 794-2624.

Adult Congenital Heart Association

by Amy Verstappen

Since its inception in 1998, the Adult Congenital Heart Association has been a voice on behalf of adults living with congenital cardiac disease. ACHA was founded by individuals with CHD and their families and continues to be an all volunteer-run, donor-funded organization. Our corporate offices are in Massachusetts, but our membership spans thirty states and ten different countries. We offer membership categories for individuals, family members, and medical professionals.

ACHA's web site, www.achaheart.org, offers expansive access to a variety of resources and a message board offering opportunities for peer support. It is regularly monitored to keep the focus on personal experience and prevent the dissemination of medical misinformation. We also offer a listserv for our members. Our newsletter offers quality medical information written by professionals, personal stories, and other resources for the ACHA community. If you would like to receive our newsletter, or are interested submitting articles, please e-mail us at info@achaheart.org

In 2000 ACHA held our first national conference, generously hosted by Dr. Michael Landzberg and the Boston Adult Congenital Heart Service. It brought together almost 100 patients, family members, and medical professionals from around the country and the world. Our next conference, co-sponsored by Loyola Medical Center, took place in April of 2002. Delayed by the events of



The Adult Congenital Heart Association offers information, resources and support for those living with congenital heart defects.

September 11th and shadowed by concerns about air travel, attendance still matched that of our first conference. At both, participants were offered top-notch information on topics ranging from new transplant technology to adoption.

Our conferences also give patients the chance to spend time together, make friends, and have fun. Our members regularly tell us that it changes their life to meet others living with congenital heart defects. This is the kind of experience that ACHA is uniquely equipped to offer. We are currently expanding our efforts to create opportunities for networking at a local level. In 2003, rather than offering one national conference, ACHA is initiating a number of regional conferences and symposia. The goal is to build outreach and awareness and promote cooperation among medical institutions. Currently planned is a symposium in Chicago on April 12th and a Mid-Atlantic Regional Conference on May 31st - June 1st. If you would be interested in more information on these events, or would like to help initiate an event in your area, please contact us.

A centerpiece of ACHA's educational efforts is giving our members the information they need to be their own best patient advocates. The

publication of the 32nd Bethesda Conference recommendations on the care of the adult with congenital heart disease has been an invaluable tool in this effort, and in September of this year ACHA voted to officially endorse these recommendations. The experiences of our members illustrate the challenges the 32nd Bethesda Conference report identifies, particularly the difficulties with health insurance, referrals, and finding appropriate adult congenital cardiac care. By educating consumers about the issues outlined in this report, we can help turn these recommendations into knowledge and action.

We also know we need to reach out to the individuals who have dropped out of the medical system, many of whom regularly show up on our message board.

ACHA and ISACCD are both committed to promoting the health and well-being of individuals living with congenital heart defects, and we look forward to more opportunities to join together on behalf of our community. We would welcome your input, your support, and your membership. By working together, we can help meet the needs of this growing, vital, and vulnerable population.

ISACCD Meeting in Chicago

Sunday, March 30, 2003 • 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 meeting of the American College of Cardiology in Chicago, IL. The ISACCD meeting will take place Sunday, March 30, 2003, at the Congress Plaza Hotel.

Highlights will be a presentation by Dr. Tal Geva on "Use of MRI in Adults with Congenital Heart Disease" and a report from Dr. Elyse Foster on the Adult Program at UCSF. All are encouraged to attend! We look forward to seeing you in Chicago.



If you will be attending the meeting, return this form by March 21, 2003, by mail, fax or e-mail.

Yes, I will attend the semi-annual meeting of the ISACCD March 30, 2003, in Chicago, IL.

Name _____

Affiliation _____

Address _____

City _____ State _____ Zip _____

Phone _____

Fax _____

E-mail _____



Send registration to:

ISACCD
1500 Sunday Dr., Suite 102
Raleigh, NC 27607

Fax: (919) 787-4916

E-mail: info@isaccd.org

Please RSVP by March 21, 2003!

International Society for



Adult Congenital Cardiac Disease

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