

May 2015

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International Society for Adult Congenital Heart Diseases

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ISACHD Newsletter

President's Message

by Paul Khairy, ISACHD President

Dear Friends,

I hope that you are all well and enjoying a beautiful spring- a season of new beginnings!



At our biannual March meeting in beautiful San Diego, several new projects and initiatives were discussed. Jouke Bokma (Netherlands), the first ever ISACHD Fellows-in-Training Representative, dazzled us with our Fellows' impressive achievements, including a survey to assess the needs and interests of ACHD fellows, progress on ISACHD's journal club, the creation of a fellowship directory, improvements to our website, and the potential development of a new resource, i.e., ACHD rounds. Susan Fernandes (USA) provided an update from ISACHD's active Cardiac Care Associates membership, including plans to coordinate an ISACHD position statement on the "ACHD Nurse Coordinator: Essential Skills and Coordination for the Outpatient Setting". Barbara Mulder (Netherlands) and Gary

Webb (USA) presented an overview of ISACHD's first position statement entitled, "The Care of Adults with Congenital Heart Disease Across the Globe: Current Assessment and Future Perspective", which is now in press in the *International Journal of Cardiology*, ISACHD's affiliated journal. Working group updates were provided on Global Education by Erwin Oechslin (Canada) on behalf of Els Pieper (Netherlands), and on Global Health Care by Disty Pearson (USA).

Updates on research projects were then discussed. The APPROACH-IS study headed by Philip Moons and Silke Apers (Belgium) was presented by Adrienne Kovacs (Canada). An impressive 4013 adults with congenital heart disease were recruited from 24 participating sites within 15 countries, establishing it as the largest multinational prospective ACHD project conducted to date. Hayang Yang and Barbara Mulder (Netherlands) provided an update on the prospective NOTE Registry to assess the efficacy and safety of NOACs in ACHD. To date, 26 centers from 10 countries have expressed an interest in participating. Finally, François-Pierre Mongeon (Canada) presented a protocol for a longitudinal study on systemic ventricular function in CCTGA.

Additional highlights of the meeting included a didactic presentation entitled, "The Subcutaneous ICD in ACHD: Is it a Game Changer" by Blandine Mondésert (Canada), which elicited much interest and discussion. Regional updates were provided by, or on behalf of, Ariane Marelli (Canada), Karen Stout (USA), Amalia Elizari (Argentina), Els Pieper, and Clare O'Donnell (New Zealand).

ISACHD is also proud of having launched new awards. The first ISACHD Lifetime Achievement Award was presented in 2014 to Dr. Joseph Perloff (posthumous). Applications for the 2015 award

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New Zealand

**Canada
Representative**
Ariane Marelli,

are now being considered (deadline September 7, 2015). ISACHD's inaugural research awards, i.e., the ISACHD Young Investigator Award and the ISACHD Cardiac Care Associate Investigator Award will be presented at 25th International ACHD Symposium from June 3-6, 2015, in Toronto, Canada.

Clearly, ISACHD is actively and vibrantly pursuing its mission of excellence in the care of adults with congenital heart disease across the globe. Please consider joining our efforts if you have not done so already (www.ISACHD.org).

With warm wishes to all,

Paul Khairy, MD, PhD
President, ISACHD

Regional News

News from Asia-Pacific

By Clare O'Donnell

A very successful 17th annual meeting of the Japanese society for Adult Congenital Heart Disease was held in January in Tokyo. The Chairperson was Morio Shoda, MD. The meeting included nearly 200 oral presentations and posters, and most impressively, 800 attendees. There were ten international speakers including Jane Somerville MD.

At the Japanese meeting Professor Lee from Taiwan reviewed some of the progress in ACHD care in the Asia-Pacific region. With an early lead from Japan, specific ACHD clinics have now developed in many countries, particularly over the last twenty years.

Membership of ISACHD however remains very modest in our region and we are keen to look at ways to develop interest and involvement.

In other news from Japan, an ACHD Committee has been established in both the Japanese Circulation Society and the Japanese College of Cardiology. These committees aim to progress education and research within these Societies.

News from South-America

Amalia Elizari and Luis Alday are working on a survey for ACHD centers in Latin America. The ISACHD received an invitation by the Latin American Society to co-organize round tables dealing with ACHD at the World Congress of Cardiology to be held in Mexico 2016.

European News

By Karen Stout

Busy times in the US!

Training: The first ACHD Board exam will be given in October 2015. The exam is open to qualified internal medicine cardiology and pediatric cardiology trained ACHD cardiologists. See www.ABIM.org for details.

The ACGME has released criteria for ACHD fellowship training, and applications are available on their site. Fellowships will be 2 years following the completion of internal medicine cardiology or pediatric cardiology. See www.acgme.org for details. There is also a proposal amongst ACHD fellowship programs to try to align application, interview and offer dates amongst programs such that the process is easier and more fair for fellows and programs. Emails will be circulated to fellowship directors with details of the proposal, including opportunities for feedback and

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**Journal Watch
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discussion.

Guidelines: The 2015 ACC/AHA Guidelines for the Management of Adults with Congenital Heart Disease are due to be published in fall 2015.

Program Accreditation: The ACHA will begin a pilot process for ACHD program accreditation, with the anticipation that programs may apply beginning in January 2016. The process is being finalized, and the criteria have been circulated for societal review.

Regional News from Europe

By Els Pieper

The ESC Congress 2015 will take place in London, from August 29 till September 2. The program is available on the ESC website. Many sessions on congenital cardiology and pregnancy and heart disease will be part of the congress.

The ESC 10th European Echocardiography Course on Congenital Heart Disease will be in Leuven, Belgium, 14-17 October. More information can be found on www.echocardiography-course.com

Research Working Group Update

By Jamil Aboulhosn

The ISACHD research working group has been tasked with the mission of identifying and helping implement multinational ACHD research projects. The current research working group members include Sue Fernandes, Paul Khairy, Jolien Roos-Hesselink, Philip Moons, Clare O'Donnell, Francois Pierre Mongeon, Gruschen Veldtman, Barbara Mulder and Jamil Aboulhosn. Two multinational projects have thus far been endorsed by ISACHD:

1. APPROACH IS- Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart Disease- International Study. This is an international multicenter project on patient reported outcomes in adults with CHD. Researchers and clinicians from 16 countries, across 4 continents, have collaborated on one of the largest studies in the field of ACHD. The study is coordinated through the University of Leuven, the principal investigator is Professor Philip Moons, PhD, RN. The steering committee includes Professors Moons, Adrienne Kovacs and Koen Luyckx. Data collection for this project commenced in April 2013 and was in January of 2014. The total sample size is >3,500 patients. Data will be analyzed during the first 6 months of 2015 and primary results of the study will hopefully be available in the second half of 2015. Sub-studies will likely be performed after the primary analyses have been conducted and reported. For further information regarding this study please contact Professor Philip Moons[Philip.Moons@med.kuleuven.be].

2. NOTE Registry- The purpose of the NOTE registry is to evaluate the efficacy and safety of non-vitamin K oral antagonists (NOACs) for thromboembolic prevention in atrial tachyarrhythmias in adult patients with CHD. The principal investigator is Professor Barbara Mulder, M.D., PhD at the University of Amsterdam. The primary objective of the registry is to evaluate the two year incidence of thromboembolic and bleeding events in consecutive CHD patients using NOACs for atrial tachyarrhythmias. The secondary objectives of the registry are to evaluate adherence to NOAC therapy and the quality of life when using NOACs, to identify CHD-specific risk factors for thromboembolism in atrial tachyarrhythmias and to evaluate the natural history of atrial tachyarrhythmias in CHD. The registry is currently enrolling subjects. For further information please contact Hayang Yang (h.yang@amc.uva.nl).

The ISACHD research working group is looking for additional multi-national studies to review and potentially endorse. Please contact the research working group chairperson, Jamil Aboulhosn, MD (jaboulhosn@mednet.ucla.edu) if you would like to propose a multi-national research protocol or get further information.

Global Health Working Group Update:

By Disty Pearson

The working group on global health is pleased to report a number of new collaborations working towards our goal of promoting lifelong care of the congenital heart patient worldwide. The first is with the "International Quality Improvement Collaborative for Congenital Heart Surgery" they focus on patient safety and quality for children receiving congenital heart surgery and are working with 42 centers around the world. Their paper in the journal of Pediatrics 10/13/14; "Reducing Mortality and Infections after Congenital Heart Surgery in the Developing World" is a remarkable example of the benefits of collaboration between CHD surgical centers looking specifically at pediatric patient surgical outcomes. Excitingly some of their collaborators have included data on adult CHD patients which they are sharing with us. At this time the opportunities seem boundless and we greatly appreciate IQIC's willingness to collaborate with us.

We are also collaborating internally within ISACHD working with Gucshen Veldtman and Jouke Bokman updating the Travel Directory that was a joint project of ISACHD and the ACHA, and now needs updated information such as email contacts. As part of that effort we are reaching out to the ISACHD Regional representatives ensuring that we include all the centers they are working with. All of these efforts will contribute to creating a data base of most if not all centers around the world who care for ACHD patients. We will then continue our efforts to partner with these centers, exchanging expertise and offering not only the excellent educational materials put together by Els Pieper and the working group on education, but also promoting close collaborations between interested centers including twinning activities.

News from Working Group on Education

On behalf of Els Pieper

The working group on education endorsed the following symposia:

- 10th International Workshop on Interventional Pediatric and Adult Congenital Cardiology, Milano, 19-21 March 2015
- Symposium on Adult Congenital Heart Disease in the 21st Century; April 17-18; Washington DC
- Toronto Symposium on Adult Congenital Heart Disease, June 3-5 2015

For endorsement of courses ISACHD requests placement of the ISACHD logo on the flyer and a discount of 10% for ISACHD members. We offer announcement of the course on our website and in the newsletter.

The working group on education is very with further development of the ACHD learning center. The learning center is available through www.achdlearningcenter.org and it is really recommendable to open this website and have a look around. Gary Webb is in charge and is doing a great job.

The ACHD learning center offers, in addition to many other resources, a web-based basic course on ACHD, with 15-minute lectures. The content of these lectures is prepared and presented by top experts and the lectures are reviewed by colleagues and edited to ensure high-quality content. More than 35 lectures are now available and we are aiming for 55. These lectures are freely available. The lectures will also be part of a formal education program for cardiology trainees all around the English speaking world, for this purpose a secure testing site is available through Cincinnati Children's Hospital. Multiple Choice Questions are developed by Jonathan Windram, Kate English, and Chris Learn, and are reviewed by Carol Warnes and myself. We will start with a module of 10 lectures, MCQ's must be answered before and after listening to the lecture, and after successful completion of the whole module a certificate will be offered. The next step will be to contact program directors to make them aware of this education program and encourage them to incorporate this in the training of their cardiology fellows.

In addition to the basic web-based teaching course, slide presentations on interventional congenital cardiology are prepared and will be available on the learning center. This process is led by Harsimran Singh.

CCA News

by Susan Fernandes

In a follow-up to the petition in the last ISACHD newsletter seeking nurses who were interested in being part of a nursing education work group, we want to thank all those who reached out and volunteered. The group has already been hard at work and has announced that they are working on an ISACHD-supported paper, "Outpatient ACHD Nurse Coordinator-Essential Skills and Role within the ACHD Team." This paper will be led by Christy Sillman, RN, MSN, nurse coordinator of the Adult Congenital Heart Program at Stanford and Joanne Morin, RN(EC), MScN of the Adult Congenital Heart Disease Program at University of Ottawa Heart Institute. According to Sillman and Morin, the paper will highlight knowledge that can't be easily found in a book, but that comes with years of experience as an ACHD nurse-an ideal resource for a nurse who is new to the field of ACHD. Some of the topics the paper will address include: organizing, coordinating, and facilitating care, holistic assessment of the ACHD patient, and providing education to ACHD patients, as well as identifying community resources. The group is now seeking additional nurses from around the globe to help write the paper. If you or someone you know might be interested in helping, please contact Christy at (CSillman@stanfordhealthcare.org).

Fellow News

ISACHD acknowledges the importance of identifying and creating opportunities for trainees to pursue research and clinical fellowships. Such training fellowships enhance experience, facilitates bilateral learning between the trainee and the fellowship centre, and hopefully also promotes ongoing collaborations beyond the fellowship program.

A coordinated series of improvements are currently being made to the ISACHD website, one of which is to clearly present current training opportunities for fellows. Damien Cullington, an ACHD fellow from Leeds, designed a survey to obtain information regarding world wide ACHD fellowship opportunities in clinical and research ACHD. ACHD program leaders will be asked to complete this online survey. The survey will take less than 10 minutes to complete. If you have any questions or if you are a program leader and want to complete the survey please contact Damien Cullington (damiencullington@hotmail.com) or Jouke Bokma (j.p.bokma@amc.uva.nl). Thank you in advance for participating.

ISACHD Introduces the new Journal Club Editorial Team

EP

A. Sami Chaouki



Interventions

Konstantin Averin



Genetics

Benjamin Landis



Imaging

Michiel Winter



Heart Failure

Jouke Bokma



Non-physician

Susan Fernandes



The journal club provides:

- High quality articles and short comments
- Update every two months with ISACHD newsletter
- Database on ISACHD website

Journal Watch

The journal watch section on the ISACHD website is now divided in two different sections. Firstly, the general section (<http://achdlearningcenter.org/category/journal-watch/>) links to the extensive journal scan on adult congenital heart disease provided by the ACHD learning center. Secondly, in the ISACHD featured articles <http://isachd.org/content/all-articles> section, selected ACHD articles are highlighted. This section includes short comments by members of the Journal Club Editorial Team. ISACHD members that wish to contribute to this section are welcome to provide suggestions for articles and comments.

Click [here](#) to view most recent ISACHD **Journal Watch** articles

Transforming ACHD Care

Marriott Downtown Eaton Centre Hotel
Toronto, June 3 - 6, 2015

25th International ACHD Symposium

REGISTER AND SUBMIT
YOUR ABSTRACT AT: www.torontoachdconference.ca



Course Director Dr. Erwin Oechslin, Toronto
Course Co-Directors Dr. Gary Webb, Cincinnati Children's
Hospital Cincinnati
Dr. Craig Broberg, Oregon Health &
Science University, Portland

On behalf of the organizing committee, I welcome you to attend the **25th International Symposium on Adult Congenital Heart Disease** (www.torontoachdconference.ca), which will be held at the **Toronto Marriott Downtown Eaton Centre Hotel from June 3 - 6, 2015**. This Symposium has been organized in partnership with the Oregon Health & Science University in Portland (Oregon), the Cincinnati Children's Hospital Medical Centre, University of Cincinnati (Ohio) and the University of Toronto and is a unique forum where medical professionals can meet their colleagues from around the world to exchange ideas and information in the field of Adult Congenital Heart Disease.

This symposium features a highly dedicated academic international faculty team, including many invited international speakers as well as speakers from the Oregon Health & Science University, the University of Cincinnati and the University of Toronto.

This year's Symposium presents **new features**:

- The **One-day Symposium 'Heart Failure, Transplant & VAD in ACHD'** is dedicated to find answers for the rapidly growing heart failure population in ACHD. The Symposium will cover all diagnostic and therapeutic aspects of this evolving challenge.
- Investigators will present **oral abstracts** related to the topic discussed in the plenary sessions.
- The **International Society of Adult Congenital Heart Disease (ISACHD)** will award the best abstract submitted by Physicians *and* by Cardiac Care Associates. The winners will receive the **ISACHD Young Investigator Award and the ISACHD Cardiac Care**

Associate Investigator Award.

Dr. Glen van Arsdell, Division-Head Cardiovascular Surgery at SickKids, Toronto, will be our **distinguished guest speaker** and will deliver the **Dr. William G. Williams Lecture**.

Cardiac Care Associates/Nurse Practitioners are integrated in the program; they also have a dedicated workshop and a Cardiac Care Associates Dinner with Philip Moons, Leven (BE) as guest speaker.

Call for Abstracts

Two oral abstracts related to the plenary session topics will be presented and discussed in the plenary session after the invited speakers have completed their presentations. There is a high chance that your abstract will be selected for an oral presentation if you submit an abstract to the following topics:

- **Coronary anomalies**
- **Hereditary aortopathies**
- **Pulmonary arterial hypertension in congenital heart disease**
- **The impact of congenital heart disease 'beyond the hearts'**

Poster Presentations: The remaining abstracts will be presented as posters throughout the meeting. We invite researchers (physicians, Cardiac Care Associates, Nurse Practitioners) to submit abstracts. This symposium is a unique opportunity to share your science and to discuss your research with the ACHD community. **Work that has been previously presented at local, national or international meetings will be considered for presentation** at this Symposium. However, **material that has been already published as a manuscript in a peer-reviewed journal will not be considered.**

Information for abstract submission: www.torontoachdconference.ca >Abstract Submission

Information at glance:

- **Abstract: Submission Deadline March 30, 2015**
- **Early Bird Registration until April 15, 2015. Special Rates for ISACHD and/or CACH Network Members in good standing.**
- **Hotel Reservation: please go to: Toronto ACHD Meeting 2015 (or www.torontoachdconference.ca). Special room rates are available until May 13, 2015: single and double room for only \$221.00 per night**

I expect the Symposium to provide the best of science and education in this area of practice. The Program is designed for all healthcare professionals working with Adult Congenital Heart Disease and should familiarize participants with the latest clinical information on the diagnosis and management for ACHD. Nursing and Congenital Cardiac Care Associates will have a major educational role within this Program.

Please visit the Event Page at Toronto ACHD Meeting 2015 (or www.torontoachdconference.ca) to learn more about the meeting and abstract submission.

On behalf of the organizing committee, I am looking forward to welcoming you to Toronto.

My best regards,
Erwin Oechslin
Chair of the Course Directors

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