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International Society for
Adult Congenital Heart Disease

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ISACHD Newsletter

President's Message

by Erwin Oechslin, ISACHD President



In this Newsletter, you will find updates from our working groups, regional representatives, cardiac care associates, and fellows-in-training.

I sincerely thank all those who have contributed to this newsletter, and the many ISACHD members involved in the numerous activities and initiatives. A special thanks to Dr. Clare O'Donnell, responsible for Global Affairs/Communications, who coordinated the contributions.

Dr. Jane Somerville: Recipient of the 2016 ISACHD Lifetime Achievement Award

I extend my sincere congratulations to Dr. Jane Somerville, London (UK), the recipient of the 2016 ISACHD Lifetime

Achievement Award. The *ISACHD Lifetime Achievement Award* recognizes sustained excellence in leadership and innovation through long-term dedication and contributions to, and achievements in, the care of adults with congenital heart disease: these attributes perfectly describe Dr. Somerville's great contributions to the field of ACHD with global impact. She has dedicated more than half of a century of her life to ACHD or GUCH, she has championed the ACHD or GUCH subspecialty amongst many other key activities which have changed the lives of many patients and the lives of the ACHD physicians. She has demonstrated exceptional leadership and vision. We are particularly proud to present Dr. Jane Somerville this Award as she is one of the founding organizers of ISACHD in 1994.

The Award will be presented to Dr. Somerville at the Semi-Annual Meeting of ISACHD during ACC.17 in Washington DC. Dr. Carole Warnes, who will present the Award, cannot attend the upcoming Semi-Annual Meeting in New Orleans. I am looking forward to the historical moment when ISACHD honors Dr. Jane Somerville, the 'mother' of GUCH.

ISACHD SURVEY

ISACHD has grown and flourished over the past two decades since its foundation in 1994. Our generation will build on the legacy of the first generation of ACHD health care professionals who had the wisdom to found ISACHD as a global umbrella for health care providers interested in advancing ACHD, a new discipline in medicine. The mission of ISACHD is to advance knowledge and training in medical disciplines pertinent to congenital heart disease in adults, to promote, maintain and pursue excellence in the care of ACHD worldwide.

The environment is changing! ISACHD must continue **defining and finding its role and its global mission** to best serve the national / regional societies, its members, health professionals and ACHD patients. Although ISACHD's mission doesn't need to be different from that of the regional organizations, ISACHD cannot be a duplicate of the national societies at a global level. ISACHD must be different and must offer a product which isn't offered by other organizations.

Dr. Adrienne Kovacs, Treasurer, prepared an ISACHD survey to seek input from all ACHD providers, researchers and trainees in order to help us set ISACHD priorities, know the expectations

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FPMR

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Past Presidents

Gary Webb, MD

1994-1996

Carol Warnes, MD

1996-1998

of the ACHD community and allocate resources accordingly. We have received feedback from more than 150 respondents including current and past ISACHD members, as well as from people who have never joined ISACHD. I express my sincere thanks to all respondents who have completed the survey and provided their feedback. Your input will guide our discussion about future priorities at the mini-retreat in New Orleans.

The current Executive Board, Past-Presidents and WG Chairs will have a **mini-retreat** with an in-depth discussion and reflection about the global mission of ISACHD and priorities during the next years. We will dedicate 3 hours in New Orleans prior to our semi-annual meeting to reflect on our mission and how to best serve our members and patients. We will share the results of the Survey and our outcome of the mini-retreat at the Semi-Annual Meeting in New Orleans (please see agenda).

A BIG THANK YOU to Dr. Adrienne Kovacs who invested days to prepare the ISACHD Survey, to analyze the results and to prepare the slides. Thank you, Adrienne. I also acknowledge the Board Members, Chairs of the Working Groups, Regional Representatives and the CCA and Fellow-in-Training Representatives for their feedback to prepare the ISACHD survey.

Journal Watch

The Journal Watch is being re-organized. In the past, there was an overlap / duplication of the Journal Watch published by the CHiP Network (www.chipnetwork.org) and ISACHD. In the future, only one Journal Watch will be published and ISACHD will be responsible for the ACHD section in the CHiP Network. Details regarding consolidation of the two Journal Watches are being discussed.

Position Statement

I congratulate the Co-Chairs Christina Sillmann (USA) and Joan Morin (Canada) and their co-authors for their excellent manuscript **Adult Congenital Heart Disease Nurse Coordination: Essential Skills and Role in Optimizing Team-Based Care. A Position Statement from the International Society for Adult Congenital Heart Disease**. The manuscript has been accepted for publication by the *International Journal of Cardiology*. We will circulate a pdf-version of the manuscript as soon as it is made available by the publisher.

The next Position Statement Adult Congenital Echocardiographic Protocol List, with contribution from an international panel under the leadership of Wei Li, London, is in preparation.

Our next **semi-annual meeting** will be on:

- Date: Sunday, November 13, 2016
- Time: 6:30 – 9:00 pm
- Place: Dauphine I & II
- Address: Hampton Inn & Suites Hotel, 1201 Convention Center Blvd

New Orleans, LA 70130

- [Agenda \(PDF\)](#)

I hope that you will join us for an evening of fruitful discussion for the future of ISACHD. I am looking forward to seeing you in New Orleans

With warm wishes to all,

Erwin Oechslein, MD, President, ISACHD

NEWS FOR FELLOWS IN TRAINING from Dr Jouke Bouma

New ISACHD survey: how do fellows acquire knowledge during training in ACHD?

The ISACHD board aims at getting involvement of more fellows in ISACHD and recognizes the importance of ACHD training. ISACHD is planning to conduct a new survey, to better understand how fellows acquire knowledge during training in adult congenital heart disease (ACHD). We

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

Jack M. Colman, MD
2006-2008

Michael J. Landzberg, MD
2008-2010

Barbara Mulder, MD
2010-2012

Curt J. Daniels, MD, 2012-2014

Paul Khairy, MD, PhD
2014-2016

previously studied the fellows' perspectives on training in adult congenital heart disease <http://www.ncbi.nlm.nih.gov/pubmed/26407046>. This study revealed that fellows perceived a need for more training in specific subspecialties. The goal of the new study is to specifically learn *how* fellows learn ACHD in the current, digital era. Insights gained from this survey will hopefully help ACHD training programs to support future trainees. Fellows who wish to participate in the survey can contact Jouke Bokma (j.p.bokma@amc.uva.nl)

CARDIAC CARE ASSOCIATES from Sue Fernandes PA-C

Congratulations to Christina Sillman, RN, MSN (co-chair, USA) and Joanne Morin, RN, MScN (co-chair, Canada) as well as their co-authors on their manuscript *Adult Congenital Heart Disease Nurse Coordination: Essential Skills and Role in Optimizing Team-Based Care. A Position Statement from the International Society for Adult Congenital Heart Disease*. The manuscript was recently accepted for publication by the International Journal of Cardiology. This was truly a global effort with co-authors from around the world including: Corina Thomet, RN, MScN (Switzerland); Deena Barber, BSN, RN (USA); Mizuno Yoshiko, RN, MSN, CNS (Japan); Hsiao-Ling Yang, RN, PhD (Taiwan); Theres Malpas, CNC (Australia); Serena Francesca Flocco, RN (Italy); Clare Finlay, RN, CNS (UK); Chi-Wen Chen, RN, PhD (Taiwan); Yvonne Balon, MN, BN, RN (Canada).

ISACHD WORKING GROUP UPDATES

Research

by Dr. Jamil Aboulhosn

The ISACHD research working group has been tasked with the mission of identifying and helping implement multinational ACHD research projects. Four multi-national 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 Kovaks and Koen Luyckx. Data collection for this project commenced in April 2013 and was completed in January of 2014. The total sample size is >3,500 patients. Data was analyzed during the first 6 months of 2015 and the rationale, design and methods were published: Apers S et al; APPROACH-IS consortium; International Society for Adult Congenital Heart Disease (ISACHD). [Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease - International Study \(APPROACH-IS\): rationale, design, and methods](#). Int J Cardiol 2015;179:334-42.
Sub-studies are in the process of being performed. 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. Preliminary registry data was presented at the European Society of Cardiology (ESC) congress in London in 2015 during the rapid fire presentation session 'Hot topics in congenital heart disease' and data was also presented at the International ACHD symposium in Skamania in 2016. The first manuscript from this registry was submitted

to the International Journal of Cardiology in October 2016 and is titled: Is initiating NOACs for atrial arrhythmias safe in adults with congenital heart disease? As of October 2016, 263 adults with CHD using NOACs have been enrolled from 37 participating centers worldwide. The inclusion will continue and new centers are welcome at this point. The registry is currently enrolling subjects. For further information please contact Hayang Yang (h.yang@amc.uva.nl).

3. **Health related quality of life in post-operative congenital heart disease patients in Pakistan-** This study seeks to determine Health Related Quality of Life (HRQOL) of CHD patients and their health related experiences following surgery undertaken in a tertiary care hospital in Pakistan. The investigators have thus far successfully enrolled 250 patients with ~ 70 of those having ACHD. Data collection is complete and analysis is ongoing. Professor Laila Akbar Ladak PhD and Dr. Babar Hasan are the principal investigators. For further information please contact Professor Ladak (Laila.ladak@aku.edu).

4. **The influence of thrombosis and anticoagulation strategies on pregnancy outcomes in women with a Fontan circulation-** This study seeks to define maternal, fetal and obstetric outcomes in pregnant women with Fontan relative to their thrombotic burden and associated use of antiplatelet and antithrombotic therapy and to determine risk factors for adverse maternal and fetal outcomes. The study additionally seeks to define placental pathology related to antiplatelet and anticoagulation strategies. For further information please contact Dr. Gruschen Veldtman (Gruschen.veldtman@cchmc.org).

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

Global Health

by Disty Pearson PA-C

The Global Health Working Group continues to work to identify effective, culturally-appropriate strategies to improve ACHD care, knowledge, and access in low and middle income countries. We are excited to report that our Global ACCESS pilot project in Pakistan is rapidly enrolling and we hope to start evaluating the data in the next months. This will further equip the group to pursue a broader needs assessment for ACHD in low and middle income countries. We continue our collaboration with the International Quality Improvement Collaborative for Congenital Heart Surgery in Developing World Countries (IQIC) which is also surveying members on ACHD care and will add to this growing body of knowledge. We also continue to assemble a list of ACHD centers worldwide and hope to be able to report further progress on this over the next months.

We look forward to the 7th World Congress of Pediatric Cardiology and Cardiac Surgery (WCPCCS) in Barcelona where we will have the opportunity to participate with our collaborators such as the IQIC in their learning session. Also we are very excited to participate in the International Congenital Heart Leadership Summit. This is the inaugural meeting of this group representing the patient and family perspective we see this initiative as key to the growth and improvement of ACHD care worldwide.

We look forward to increasing our members and hope to hear from all of you about your ideas about ACHD care in LMIC.

Education

by Dr. Erwin Oechslin

The WG on Education is being reorganized. Dr. Els Pieper, Groningen, has been serving the WG on Education since 2012 and has been responsible for the 15 Minute Learning Modules on ACHD since 2012, and has served as Chair of the WG on Education since 2014. She resigned from this Position in August 2016 because of the many clinical duties as a result of the ACHD tsunami which doesn't allow her to meet her and our expectations. I sincerely thank Dr. Els Pieper for her time and commitment to the WG on Education and to ISACHD as Chair of the WG on Education. I'm very glad to let you know that she remains a member of the WG on Education and still serves as Regional Representative for Europe. The WG on Education is being reorganized so that it can continue her mission to improve education in ACHD.

I express my sincere thanks to Dr. Gary Webb, Editor in Chief of the Editorial Board of the ACHD Learning Center, and his team for the tremendous effort to improve the Learning Centre (www.achdlearningcenter.org) as an e-hub for education in ACHD. The Cardiology Fellow Test Center, a comprehensive testing program for cardiology trainees is his current main focus. This testing program offers the trainees a comprehensive overview of topics related to ACHD.

I have already highlighted the new arrangement for the Journal Watch in the Section 'President's Message'.

REGIONAL NEWS

Asia Pacific

by Dr. Clare O'Donnell

Professor Niwa, President of the Asia Pacific Society of Adult Congenital Heart Disease, chaired the business meeting of APSACHD which was held during the recent Asia Pacific Pediatric Cardiac Society meeting in Shanghai, China. The meeting was attended by delegates from China (the host country), India, Indonesia, Japan, Korea, Malaysia and the Philippines. Future strategies including establishment of working groups, a research committee and development of the web page were discussed. A one day session was held during the meeting focused on adult congenital heart disease including program development and specific disease topics. Planning is underway for the next meeting which will be held in 2018 in Bali, Indonesia.

Upcoming ACHD meetings for 2017 include the **19th Congress of JSACHD** which will be held Tsu City, Mie from **January 14th and 15th** - Satellite symposium: January 13th (Mie was the location for the G7 Summit held this year). The chairperson is Tomoaki Iked, Dept Obstetrics, Mie Univ. <http://procomu.jp/jsachd2017/>

We are very pleased to add a welcome to the **2nd International Congenital Cardiac Cocktail on ACHD** to be held **January 11-13, 2017** at **Shangri-La Hotel Bangkok** (please contact Dr. Alisa Limsuwan for additional information at alimsuwan@yahoo.com or www.adultcongenitalcardiology.com) and the inaugural **ACHD Symposium 2017** to be held in Queenstown, New Zealand **30 November to 2 December**. www.achd.nz/ www.achd2017.com.

United States

by Dr. Karen Stout

ACHD fellowship application season continues, with more fellowships applying for ACGME certification - there are currently 7. ACHD Guidelines are progressing and should be published early 2017. ACHA program accreditation is ongoing, with pilot sites having completed the accreditation process, and the initial open application period is ongoing with many programs from around the US putting in an application.

Europe

by Dr. Els Pieper

After a successful ESC congress with many interesting sessions dedicated to adult congenital heart disease, the European adult congenital heart disease community now looks forward to the yearly **EuroGuch** meeting. This meeting is currently the most prestigious adult congenital heart disease conference in Europe. Next year the meeting will take place on the **5th and 6th May** in beautiful **Lausanne, Switzerland**. A truly international faculty with opinion leaders from both Europe and North America will cover burning topics in adult congenital heart disease.

The focus of the meeting will be on novel therapeutic strategies of anticoagulation, heart failure, pulmonary hypertension and systemic hypertension, novel interventional therapies for valve dysfunction, and arrhythmia, and problems beyond heart disease (including sexuality and depression).

We expect more than 200 participants from all over Europe attending the meeting and hopefully also professionals from other areas in the world will join us.

More information can be found through <http://wp1.euroguch.com/>

And....THE ISACHD SURVEY

by Dr. Adrienne Kovacs

In October 2016, ISACHD launched a survey to help us (i) learn how we can best meet the needs and interests of the international ACHD community, (ii) set ISACHD priorities, and (iii) understand your expectations and allocate our resources appropriately. We are pleased to report that we had over 150 respondents, including current ISACHD members, past ISACHD members, as well as people who have never joined ISACHD. Respondents included physicians, nurses, advanced practice providers, researchers, administrators, and patients. If you completed the survey, thank you for answering our questions and supporting the ISACHD mission! Results will be shared at the November 13th ISACHD meeting at ACC in New Orleans and in the next ISACHD newsletter. Stay tuned!
