

May, 2014

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International Society for  
Adult Congenital Heart Disease

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PhD  
Montreal Heart  
Institute  
Montreal, Quebec,  
Canada

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General Hospital,  
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## ISACHD Newsletter

### President's Message

*by Paul Khairy, President*

Dear ISACHD Members,



It is an honor and a great pleasure to introduce this newsletter as ISACHD's 11th president. The year 2014 marks the 20th anniversary since Dr. Gary Webb was elected as the inaugural president of our society. Over the past two decades, ISACHD has grown and flourished along with the field of adult congenital heart disease to become a truly international society, with membership that spans over 25 countries across the world. Throughout its rich history, ISACHD has remained faithful to its mission of promoting, pursuing, and maintaining excellence in the care of adults with congenital heart disease.

We are indebted to the many passionate women and men who have generously dedicated their time and expertise in leadership roles. At our last symposium held on March 29, 2014 in

Washington DC, a new slate of ISACHD executives and officers was introduced: Dr. Erwin Oechslin (Toronto) was named President-Elect, Dr. Adrienne Kovacs (Toronto) Treasurer, and Dr. Gruschen Veldtman (Cincinnati) Secretary, with Dr. Curt Daniels (Columbus) transitioning into the past-president role. Dr. Karen Stout (Seattle) was appointed USA representative, Dr. Ariane Marelli (Montreal) Canadian representative, Dr. Els Pieper (Amsterdam) European representative, Dr. Clare O'Donnell (Auckland) Asian-Pacific representative, and Dr. Amalia Elizari (Buenos Aires) South American representative. Congratulations to all and welcome aboard!

We are also grateful to the individuals who completed their ISACHD mandates with flair: Drs. Barbara Mulder, Philip Moons, Koichiro Niwa, Luis Alday, Bill Davidson, Helmut Baumgartner, and Desiree Fleck. Their service and leadership inspire us all.

ISACHD's dedication to advancing care and knowledge in adult congenital heart disease is reflected by active Global Health Care, Education, and Research initiatives, for which brief updates are provided in this newsletter. We are pleased to welcome the new chairs of these working groups: Disty Pearson (Boston), Global Health; Dr. Els Pieper (Amsterdam), Global Education; and Dr. Jamil AboulHosn (Los Angeles), Global Research. We also welcome Dr.

Columbus, OH,  
USA

**USA  
Representative**

Karen K. Stout  
M.D.  
Adult Congenital  
Heart Disease  
Program  
University of  
Washington  
Seattle, WA

**South America  
Representative**

Dr. Maria A Elizari  
Inst. Cardiologia  
Hospital Espanol  
Moreno,  
Buenos Aires

**Europe  
Representative**

Dr. Els Pieper  
University Hospital,  
Groningen,  
Netherlands

**Asia-Pacific  
Representative**

Dr. Clare P  
O'Donnell  
Paediatric/Congenital  
Cardiology  
Starship Hospital,  
Auckland,  
New Zealand

**Canada  
Representative**

Dr. Erwin Oechslin,  
General Hospital,  
Toronto,  
Ontario, Canada

**Journal Watch  
Editor**

Gruschen  
Veldtman, FRCP,  
MBChB  
Heart Institute  
Cincinnati  
Children's Hospital,  
USA

**Executive  
Director**

Peter Kralka  
FPMR  
Raleigh, NC, USA

Susan Fernandes (Palo Alto) as representative of ISACHD's Cardiac Care Associates. In order to reach out to and better serve the needs of adult congenital heart disease fellows throughout the globe, we are pleased to introduce a trainee representative on ISACHD's executive, Dr. Jouke Bokma (Amsterdam).

Please visit our website at [www.isachd.org](http://www.isachd.org) to learn more about ISACHD, browse through the journal watch page for the latest ACHD publications, and view upcoming conferences endorsed by our society. If you have not already done so, please consider registering to become an ISACHD member. The fees are modest but the support will go a long way in growing and strengthening our society.

I sincerely look forward to learning from and working with you in the upcoming years. ISACHD is your society- please get involved!

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## Regional News

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### Education Working Group

*By Els Pieper*

The education working group is continuously busy with establishing the ACHD learning center under the inspiring leadership of Gary Webb. The resources on or linked to the website are expanding. The web-based basic teaching course (led by Els Pieper, Groningen) is growing and about 20 of the 55 lectures are now placed on the website. MCQ's are being prepared by Jonathan Windram and Kate English, so the certification process is in preparation.

The education working group has endorsed the following symposium: "International Adult Congenital Heart Disease Annual Symposium," a conference, which Cincinnati Children's Heart Institute will be hosting from June 10-13, 2014, at the Hilton Netherland Plaza in Cincinnati. More information is at <http://www.cincinnatichildrens.org/achdprogram>



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### News from Asia-Pacific

*By Clare O'Donnell*

The Asia Pacific Society for Adult Congenital Heart Disease met in March at the very successful 5th Congress of the Asia Pacific Pediatric Cardiac Society meeting themed

### **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

Jack M. Colman,  
MD  
2006-2008

Michael J.  
Landzberg, MD  
2008-2010

Barbara Mulder,  
MD  
2010-2012

Curt J. Daniels,  
MD, 2012-2014

"Translating Recent Advances to Regional Needs", held in New Delhi, India. Under the leadership of Professor Niwa from Japan, fifteen countries from our region have current representation in APSACHD with interest also from newer members of the APPCS.

Dr Snehel Kulkarni coordinated a day of ACHD invited presentations and abstracts. An interesting session focused on service organisation for care of adult congenital heart patients. Contributions from lead clinicians from different centers highlighted the diversity of the challenges facing our group and the need for us to support and learn from each other, as we strive to improve local service delivery. Other presentations examined late outcomes in common congenital lesions, and the afternoon was concluded with very interesting abstracts from across the region.

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### **European Experience from Amsterdam**

*By Folkert Meijboom*

The 5th European Meeting on Adult Congenital Heart Disease. Amsterdam, April 10-11, 2014.

This European GUCH meeting was the first "stand-alone" meeting, was aimed exclusively at the Adult Congenital Heart Disease, and for the first time, organized by three organizations: ESC WG ( Folkert Meijboom), EACTS (European Association of Cardiothoracic Surgeons, Mark Hazekamp) and ISACHD (Barbara Mulder). "West Indisch Huis" was the meeting's venue, which combined an elegant architecture and nice atmosphere, including its beautiful courtyard (see picture) of a historical building (1617) with modern congress facilities.



A total of 181 participants were registered over the 2 days course. Participants came from all over the world, in total of 22 countries.

The main topics of the two-days program were tricuspid valve surgery, RV to pulmonary artery conduits, and the arterial switch operation. Both cardiological and surgical points of view were presented on each topic. Because of the use of voting pads and ample scheduled time for discussion the audience participation was very lively and interesting.

Other issues discussed were new developments in cardiac devices, shunts and the role of NOACs in ACHD. The Jane Somerville keynote lecture was given by professor Barbara Mulder, which focusing on gender differences in outcomes of ACHD patients, and also on general population and treating physicians... As long as men are being supported by women, men shouldn't need to worry too much.

The social part of the meeting, apart from the relaxing lunches in the open courtyard, consisted of a boat trip through the beautiful canals of Amsterdam, and a congress dinner for all participants.

Joint meetings like this should be encouraged for all over the world. Interdisciplinary collaboration between regional and global bodies may improve our insight into optimal care for ACHD patients.

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### **European News**

*By Els Pieper*

At the ESC Congress in the beautiful Barcelona (30 August - 3 September) cardiologists from around the world will gather around the theme of 'innovation and the heart'. There is an ample opportunity to update our knowledge and to meet each other as ACHD specialists. Sessions are being organized concerning ASD, interventional techniques (2 sessions, organized together with ISACHD and with the ESC working group, on Valvular heart disease); pulmonary vascular disease and the Fontan circulation, Marfan syndrome, pregnancy and devices. Additionally, interactive case presentations and abstract sessions will be presented.

The 9th European Echocardiography Course in Congenital Heart Disease will be held in Timisoara, Romania, from Wednesday, October 15, to Saturday October 18, 2014. This course will provide a thorough overview of Echocardiography in Congenital Heart Disease, and will be aimed at pediatric and adult congenital cardiologists, and at echo-technicians as well. The course will prepare for the accreditation exam of 'Congenital Heart Disease Echocardiography' organized by the EAE/AEPC. This accreditation exam will take place at the EuroEcho in Vienna, December 3-6 2014.

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### **ISACHD Fellows**

*By Jouke Bokma*

The new ISACHD board aims at getting involvement of more fellows-in-training. Jouke Bokma, research fellow from Amsterdam, is now appointed as the fellow representative to work on this goal. He will be conducting an online survey, together with Gruschen Veldtman, for ACHD fellows-in-training, as well as for research fellows. By doing this, we aim to establish an overview of current fellows with experience and their perspectives. With this knowledge, ISACHD will attempt to offer more attractive opportunities for fellows involved in international collaboration. Furthermore, this survey may provide a valuable insights in fellows' perspectives on training programs and areas for improvement. The survey is currently being designed and will be conducted after the ethics committee approval. Fellows who wish to complete the survey can contact Jouke at [t.j.p.bokma@amc.uva.nl](mailto:t.j.p.bokma@amc.uva.nl).

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### **ISACHD Global Health Initiatives**

*By Disty Pearson*

The mission of ISACHD Global Health Initiatives is to "promote lifelong care of the congenital heart patient worldwide" that demonstrates, both, culturally and socially sensitive by providing education and a consulting network.

We will be working to identify health professionals involved in the care of adults or adolescent patients with congenital heart disease, internationally, and particularly in underdeveloped countries, through our colleges from ACHD, pediatric cardiology, and general cardiology. We hope to create providers database of the CHD care internationally, who deliver care through medical missions, as well as their "in country" contacts. We ask our members assistance in this process to help identify these contacts. Once identified, we will collectively reach out to these providers and provide them with information on the care of the Adult with CHD, which they can incorporate into their international efforts. The information provided will include educational modalities that ISACHD has developed and perhaps additionally, virtual classrooms, information provided electronically on drives, twinning efforts, and Educational exchanges. We see this opportunity to progress on individual basis with trusting relationships developing between our ACHD colleagues, and the groups providing direct care.

We will also work to identify local patient groups and provide contacts for them to those with experience in patient advocacy.

Please contact me at [Disty.pearson@cardio.chboston.org](mailto:Disty.pearson@cardio.chboston.org) if you would like to participate, and, or if you know of any groups who reach out to underdeveloped countries.

#### **ISACHD Research Working Group**

The ISACHD research working group has been tasked with the mission of identifying and helping implement multi-national ACHD research projects. The first such project to be endorsed by ISACHD is APPROACH-IS, the acronym for Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease - International Study. More information regarding study rational, aim, methods, and consortium are available at [www.approach-is.net](http://www.approach-is.net).

APPROACH-IS is an international, multicenter research project on patient-reported outcomes in adult patients with congenital heart disease. Researchers and clinicians from 16 countries, across 4 continents collaborate in one of the largest studies in the field of congenital heart disease ever conducted.

The vision of the consortium is for APPROACH-IS to be a project that

- has a high impact on clinical practice and research in the field of adult congenital heart disease;
- allows us to provide a truly international perspective on patient-reported outcomes.

This study is coordinated by the University of Leuven (KU Leuven), the PI is Professor Philip Moons PhD, RN. The steering committee includes Professor Moons, Dr. Adrienne Kovacs and Prof. Koen Luyckx, PhD.



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

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## Journal Watch

Click [here](#) for submitted Journal Watch contributions....