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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,  
Toronto,  
Ontario, Canada

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Veldtman, FRCP,  
MBChB  
Heart Institute  
Cincinnati Children's  
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### Past President

Curt J. Daniels, MD,  
FACC  
Nationwide  
Children's Hospital  
The OH State

## ISACHD Newsletter

### President's Message

*by Paul Khairy, ISACHD President*



Dear Friends,

In this newsletter, you will find updates from our working groups, regional representatives, cardiac care associates, and fellows-in-training. Our Journal Watch highlights key recent publications relevant to adults with congenital heart disease across several themes.

I sincerely thank the many ISACHD members involved in our numerous initiatives including Global Working Groups on Education, Health, and Research, position statements, Journal Watch, website updates, fellows-in-training projects, cardiac care associate activities, nomination and selection committees, and conferences across the globe organized in partnership with ISACHD.

It has been an absolute privilege to serve as ISACHD's President over the past two years. I have been truly humbled by the

enthusiasm, energy, and dedication of our members who are deeply committed to advancing our mission of promoting, maintaining, and pursuing excellence in the care of adults with congenital heart disease worldwide. It has been a tremendous honor working with, and learning from, you all.

Our next biannual meeting will be on:

- Date: Sunday, April 3, 2016
- Time: 6:30 - 9:00 PM
- Place: Joliet Room, 3rd floor, Hilton Chicago
- Address: 720 South Michigan Avenue, Chicago, Illinois, 60605

The preliminary agenda can be downloaded by clicking [here](#). In addition to updates and discussions, the meeting will feature a presentation by Dr. Gruschen Veldtman entitled, "Fontan and liver disease: a practical approach".



**ACTELION** Sponsorship Support Provided by Actelion Pharmaceuticals US, Inc.

Our nomination committee has recommended the following individuals for the 2016-2018

ISACHD officer positions:

- President: Erwin Oechslin
- President-Elect: Helmut Baumgartner
- Secretary: Gruschen Veldtman
- Treasurer: Adrienne Kovacs
- Immediate Past-President: Paul Khairy

University  
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

Ariane Marelli,  
MD  
Royal Victoria  
Hospital  
Montreal,  
Quebec, Canada

#### Journal Watch

##### Editor

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

#### Executive Director

Peter Kralka  
FPMR  
Raleigh, NC, USA

#### Past Presidents

Gary Webb, MD  
1994-1996

If you are interested in an executive position or wish to become more involved in ISACHD activities, please contact either Curt Daniels ([Curt.Daniels@nationwidechildrens.org](mailto:Curt.Daniels@nationwidechildrens.org)) or myself ([paul.khairiy@umontreal.ca](mailto:paul.khairiy@umontreal.ca)).

I hope that you will join us for an evening of camaraderie, appetizers, and drinks (open bar!). I look forward to seeing you in Chicago!

Sincerely,

Paul Khairy, MD, PhD  
President, ISACHD

## Regional News

### News from Asia-Pacific

*By Clare O'Donnell*

It is very pleasing to note several meetings and symposia with an ACHD focus in our region over recent months.

In Hyderabad in October 2015 the Indian GUCH society was inaugurated during the Annual Paediatric Cardiac Society Conference. In addition to a new website ([www.achdindia.com](http://www.achdindia.com)) which has been developed to assist both professionals and patients a symposium was held with contributions from local experts including Drs Snehal Kulkarni and Anita Saxena and invited international speakers Dr Jane Somerville, Dr Koichiro Niwa and Dr Clare O'Donnell.

In addition during the annual Cardiac Society meeting a half day symposium was held in feb 2016.

In Thailand in January an ACHD symposium was convened over 2 days again featuring a strong faculty of local and international speakers.

The Korean GUCH society held their annual meeting (GUCH Symposium 2015) on December 5th, 2015 with central theme of the Single Ventricle together with a satellite symposium on pulmonary hypertension.

Dr. Niwa, Dr. Akagi and Dr. Sakamoto were the invited speakers from the Japanese GUCH Society.

The Annual meeting of Japanese Society for ACHD was held in January 16-17 in Osaka, The title of the meeting this time was the multidisciplinary team approach. The number of attendants was 500 and a lot of surgical issues were discussed.

### Nursing News

*By Sue Fernandes*

We are pleased to announce that the ISACHD-supported paper, "Adult Congenital Heart Disease Nurse Coordination: Essential Skills and Role in Optimizing Team-Based Care" has been completed and is being reviewed by ISACHD leadership for consideration as an ISACHD position statement paper prior to submission. Congratulations to Co-Chairs Christy Sillman, RN, MSN (US) and Joanne Morin, RN(EC), MScN (Canada) as well as the co-authors Corina Thomet, RN, MScN (Switzerland); Deena Barber, BSN, RN (US) MizunoYoshiko, 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); Susan M Fernandes, LPD, PA-C (US). This was truly a global effort that has resulted in an invaluable addition to the ACHD literature.

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

Next up: Are you an advanced practice provider (nurse practitioner, physician assistant) in ACHD? Do you like to write? We are seeking volunteers to begin a working group on the role of the advanced practice provider in ACHD with the goal of putting together a paper similar to what the nursing group has accomplished. If you are interested please email [smf14@stanford.edu](mailto:smf14@stanford.edu). Please include a statement of how you might add value to this paper and include your CV. Again we are hoping for a global perspective so please reach out to those you know in ACHD throughout the world.

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### Opportunities for International Fellowships in ACHD to Appear Online Soon!

*By Jouke Bokma*

ISACHD has collected information from program leaders of ACHD centers throughout the world to inform prospective fellows on fellowships in ACHD. Damien Cullington from Leeds has created an online survey with Survey Monkey, which was completed by program leaders of over 30 centers worldwide. The survey contained information on both clinical and research fellowships opportunities. The full list of centers who completed the questionnaire will be posted on the ISACHD website ([www.isachd.org](http://www.isachd.org)) soon. In addition, this list will contain links to site-specific information for prospective fellows. Although we collected information from many centers worldwide, some sites with interesting training opportunities may still be missing on the online list. Please contact Jouke Bokma ([j.p.bokma@amc.uva.nl](mailto:j.p.bokma@amc.uva.nl)) if you want to provide additional information and include your ACHD training program (clinical and/or research) on the website.

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### Global Health Working Group Update:

*By Disty Pearson*

The global health working group continues to strive for greater collaboration in ACHD care with the goal of increasing awareness, training, and access in low and middle income (LMI) countries. **The International Quality Improvement Collaborative for Congenital Heart Surgery in Developing World Countries (IQIC)** has been a major partner in our endeavors. The IQIC was launched to facilitate a collaborative comprised of healthcare teams from around the world working to create a culture of patient safety and sustainable quality improvement (QI) infrastructures for children receiving congenital heart surgery in resource-limited settings. The IQIC's mission is to reduce mortality and major complications for children undergoing congenital heart surgery. Today, there are currently 45 sites in 22 different countries enrolled with the IQIC. In 2015, Global Health Chair Disty Pearson worked in collaboration with the IQIC and presented an abstract Adult Congenital Heart Disease Surgery in the Developing World reporting on 857 adult congenital surgeries in low and middle income countries.. This abstract won the ISACHD award for best research by a non-physician at the 2015 ACHD course in Toronto.

Building on this initial partnership, we are working closely with the IQIC team to execute a pilot study to illuminate ACHD care access and awareness in developing countries. This study, entitled **Global ACCESS (Adult Congenital Cardiac Needs Evaluation Systems)**, will be piloted at four care centers in Pakistan. The research team is being led by Babar Hasan, MD and Laila Ladak, RN; additional team members include Kathy Jenkins, MD, MPH, Disty Pearson, PA-C, Muneer Amanullah, MBBS, Kaitlin Doherty, and Amy Verstappen. The objectives are to identify who is currently executing care for ACHD patients in Pakistan, and to describe the burden of ACHD care and the spectrum of procedures currently performed. In addition, both health care providers and patients will be surveyed about their perceptions of ACHD care needs and their interest in learning more about the issue. Once this pilot has been evaluated and data are identified, we plan to expand this needs assessment to centers in LMI countries around the world. The goal is to identify effective, culturally-appropriate strategies to improve ACHD care knowledge and access. To complement these efforts, Disty Pearson and Amy Verstappen will be participating in IQIC's training and audit sessions.

The Global Health Working group has also continued its focus on the **International ACHD Program Survey and Directory**. The goal of this survey is to create a global directory of sites that currently provide care for ACHD patients in their area. As of January 1016 we had contacted 83 ACHD programs

worldwide; 28 ACHD programs from 20 countries had responded. We continue to work to promote participation and identify new sites for inclusion, particularly in underserved areas.

## Journal Watch

The journal watch section on the ISACHD website is now divided into 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

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