Dear Friends,

It is a great pleasure to introduce this newsletter as ISACHD's 12th president. We planned to publish this newsletter at the beginning of June 2016, but I was on sick leave from May 24, 2016 to July 4, 2016 which delayed many projects. I am back with full energy.

It is a great honor and privilege to lead an international group of passionate physicians, cardiac care associates, and fellows-in-training who have dedicated their career to promote, to maintain and to pursue excellence in the care of adults with congenital heart disease worldwide. ISACHD, the global umbrella organization for adult congenital heart disease (ACHD), 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. ISACHD is indebted to the past presidents, past board members and many health professionals who generously dedicated to their vision and leadership to the mission of ISACHD: to advance knowledge and training in medical disciplines pertinent to congenital heart disease in adults. We have the mandate to continue the rich and successful history of ISACHD!

I have set the following priorities for the next two years:

• **Consolidation, Continuity and Sustainability** of the many projects in global education, global health care and global research. This was the main reason to avoid major changes on the Executive Committee and to ask Dr. Adrienne Kovacs and Dr. Gruschen Veldtman to be on the Board for a second term. The current Board Members have an in-depth background knowledge about different projects which would get lost if we had exchanged the entire Board. And even importantly, Dr. Adrienne Kovacs and Dr. Gruschen Veldtman have done a fantastic job, are very engaged and committed to ISACHD, and provide high value input to move ISACHD forward.

• **Global Mission of ISACHD:** ISACHD is the global umbrella organization of national / regional societies in ACHD. ISACHD will continue to define and to find 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 has to be different and must offer a product which isn't offered by other organizations. The present Board will have an in-depth discussion and reflection about the global mission of ISACHD during the next year and will dedicate a half day in New Orleans prior to the biannual meeting to continue this discussion and reflection.

• **Global Affairs and Communication:** We have introduced the new Position 'Global Affairs and Communication'. This position is very timely for ISACHD as a global umbrella organisation to improve communication among the different regions and among the members.
I am very grateful to Dr. Clare O'Donnell, Auckland, New Zealand, who accepted this position.

- **Regional representatives.** There is a gap on the global map: China and Africa. I will try to close this gap during the next year. Regional representation from these important and large regions are critical for a global organisation as their challenges and barriers in congenital heart disease are different from those in North America or Europe.

At our last biannual meeting in Chicago on April 3, 2016 (during the ACC Scientific Sessions), a slate of ISACHD Executives and Officers was introduced.

- Dr. Helmut Baumgartner, Muenster (Germany), President-Elect
- Dr. Adrienne Kovacs, Portland (OR), Treasurer
- Dr. Gruschen Veldtman, Cincinnati (OH), Secretary
- Dr. Paul Khairy, transitioned to the role of the Past-President
- Dr. Clare O'Donnell, Auckland (NZ), Global Affairs and Communication.

The three Working Groups - Global Education, Global Health Care and Global Research - reflect our global mission and are one of the backbones of our activities. I am very thankful to the chairs of these Working Groups who continue their very important work and leadership for another term to stand for continuity (they provide an update about their activities below):

- **Global Health Care:** Disty Pearson, Boston (MA)
- **Global Education:** Dr. Els Pieper, Groningen (NL)
- **Global Research:** Dr. Jamil Aboulhosn, Los Angeles (CA).

The Regional Representatives are the important link to the different regions:

- **Asian-Pacific:** Dr. Clare O'Donnell, Auckland (NZ)
- **Canada:** Dr. Ariane Marelli, President CACH Network, Montreal (QC)
- **Europe:** Dr. Else Pieper, Groningen (NL)
- **South America:** Dr Maria Elizari, Buenos Aires (Argentina)
- **USA:** Dr. Karen Stout, Seattle (WA)

Integration of the Non-Physicians and Fellows in-training is one of my major goals to strengthen ISACHD as a representative of all care providers:

- **Non-Physicians:** Susan Fernandes, Palo Alto (CA)
- **Fellows in-Training:** Dr. Jouke Bokma, Amsterdam (NL)

Peter Kralka, Raleigh (NC) will be the Executive Director of the ISACHD office and provide administrative support for ISACHD.

I congratulate to all, I welcome them and I am looking forward to working with them during the next two years to strengthen the mission and position of ISACHD as a global organization!

**ISACHD RESEARCH AWARDS 2016**

I would like to extend my sincere congratulations to the recipients of our ISACHD Research Awards, which were presented at the 26th International Symposium on Congenital Heart Disease in the Adult at the Skamania Lodge Meeting, in Stevenson (WA), from June 1-4, 2016

The ISACHD Young Investigator Award was presented to Jim Vehmeijer, MD (Amsterdam, NL) for his abstract entitled, 'Performance of Guideline Indications for ICD Implantation with Congenital Heart Disease'.

The ISACHD Cardiac Care Associates Research Award was presented to Pamela Miner (Los Angeles, CA) for her abstract entitled, 'Contraceptive Practices of Women with Complex Congenital Heart Disease: A Multi-Center North American Experience'.

**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 Español
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

**Journal Watch Editor**
Gruschen Veldtman,
FRCP, MBChB
Heart Institute
Cincinnati Children's Hospital, USA
From the left: Adrienne H. Kovacs, PhD, Pamela Miner, NP, Jim Vehmeijer, MD, and Dr. Jamil Aboulhosn, Research Subgroup Chair

**CALL for NOMINATIONS FOR THE ISACHD LIFETIME ACHIEVEMENT AWARD 2016**

ISACHD launched ISACHD Lifetime Achievement Award under the Presidency of Dr. Paul Khairy in 2014. The first ISACHD Lifetime Achievement Award was presented in 2014 to Dr. Joseph Perloff (posthumous). In 2015, Dr. Gary Webb was acknowledged and honored for his great contributions with global impact to the ACHD community by presentation of the second ISACHD Lifetime Achievement Award at the biannual meeting in Orlando in November 2016.

Applications for the 2016 award are now being considered (deadline Monday, September 5, 2016). Please find information regarding Attributes and Criteria and the Nomination Process at the following URL: [http://isachd.org/content/isachd-lifetime-achievement-award](http://isachd.org/content/isachd-lifetime-achievement-award)

**SAVE THE DATE**

I invite you to join us for our ISACHD Semi-Annual Meeting in New Orleans, Sunday, November 13, 6:30 - 9pm. The meeting will take place at the Hampton Inn & Suites New Orleans Convention Center Hotel, located at 1201 Convention Center Boulevard.

**ISACHD is actively pursuing its global mission** of excellence in the care of adults with congenital heart disease. Please visit our website at [www.isachd.org](http://www.isachd.org) to learn more about ISACHD and consider joining our efforts if you have not done so already. Please **renew your membership or 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 am looking forward to learning from and working with you, to strengthen the ties to the different regions around the globe and to strengthen to mission of ISACHD in the upcoming years!

With warm wishes to all,

Erwin Oechslin, MD, President, ISACHD
The 7th World Congress of Pediatric Cardiology and Cardiac Surgery, scheduled July 16-21, 2017 will relocate from Istanbul, Turkey to Barcelona, Spain

on behalf of Dr. Erwin Oechslin

Please click here for details

Regional News

THE 26th ANNUAL INTERNATIONAL SYMPOSIUM ON CONGENITAL HEART DISEASE IN THE ADULT - Skamania, Washington June 2016

By Dr. Adrienne Kovacs (on Behalf of the OHSU team)

The 26th Annual International Symposium on Congenital Heart Disease in the Adult was held in Skamania, Washington in June 2016. The planning committee, led by Craig Broberg, was thrilled with the attendance - there were almost 250 registrants representing 12 countries and 36 North American states or provinces. The interdisciplinary nature of ACHD care was also highlighted by the fact that one-third of attendees were non-physicians.

The successful meeting lived up to the theme of 'Innovation Past and Present.' With almost 100 talks, highlights included presentations by Ariane Marelli (The 21st century patient: The convergence of information technology and empowerment), Roberta Williams (The evolving surgeon-cardiologist relationship), and Carole Warnes (Lessons from the past, directions for the future). There were also over high-quality 50 poster abstract presentations. Pamela Miner won the ISACHD Cardiac Care Associate Research Award for her abstract entitled, 'Contraceptive practices of women with complex congenital heart disease: A multi-center North American Experience.' Jim Vehmeijer won the ISACHD Young Investigator Research Award for his project entitled, 'Performance of guideline indications for ICD implantation in adults with congenital heart disease.'

Attendees commented on the ideal combination of science/education plus socializing/networking. Highlights include the David Sahn recognition evening, an entertaining trivia event hosted by Luke Burchill and Eric Krieger, a Sternwheeler Dinner Cruise, and afternoon hikes.

Please save the date for the 27th Annual Symposium to be held in Cincinnati, Ohio on September 14-17, 2017.

News from Asia-Pacific

By Clare O'Donnell, Regional Representative

China: APSACHD 2016, Shanghai (one day meeting) will be held along with APPCS Congress, Oct 20-23 (http://www.appcs2016.org).
A one-day session on ACHD was held in Guangzhou, China, during the 18th South China International Congress of Cardiology. This was the first dedicated ACHD session in China.

Japan: 14th ACHD Seminar, Tokyo, Japan (2 day teaching seminar) will be held, June 25, 26th. (http://www.jsachd.org/event/seminar.html)
The 80th Congress of Japanese Circulation Society was held March 18-20 in Sendai, Japan. During that meeting six symposia were held including an educational session. The Japanese Circulation Society is the biggest Cardiology meeting in Japan, and the number of symposia on ACHD is increasing year by year reflecting increasing interest of cardiologists in the ACHD field.
Korea: The Korean GUCH symposium will be held in Seoul, November 5th.

Thailand: The 1st Bangkok International Adult Congenital Cardiology Symposium was held January 21-22, 2016 and directed by Dr. Alisa Limsuwan. The program included renowned invited international speakers and local experts in a diverse and dynamic program. Given the success of the 1st Bangkok International Adult Congenital Cardiology, plans are already underway for the 2nd International Congenital Cardiac Cocktail on ACHD on 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

New Zealand: Planning is underway for the inaugural ACHD symposium for Australia/New Zealand to be held in Queenstown 30 Nov to 2 Dec. www.achd.nz

News from Europe
By Els Pieper, Regional Representative

The main upcoming event that needs to be mentioned is the yearly ESC Congress. This year Rome is hosting the congress where more than 30,000 cardiologists and other professionals will gather around the theme 'The Heart Team'. Certainly multidisciplinary collaboration is core business for adult congenital cardiologists and there will be many sessions devoted to congenital cardiology, congenital cardiothoracic surgery and pregnancy and heart disease and pediatric cardiology. Again we will have a joint session of ISACHD and the ESC grown-up congenital heart disease working group. It will be wonderful to meet each other in this historic city. Save the date: Saturday 27 - Wednesday 31 August 2016.

From 16-19 November the 11th European Echocardiography Course on Congenital Heart Disease will take place in Bordeaux - see www.echocardiography-course.com for more information.

News from USA
By Karen Stout, Regional Representative

The first ACHD Board Exam was given in October 2015, with over 175 people who are now board certified ACHD cardiologists. Congratulations to all who passed the exam. ACHD fellowship training is advancing as well, and there are now 7 seven ACGME accredited ACHD fellowships in addition to more fellowships being formalized. A group of ACHD fellowship directors continues to meet regularly under the leadership of Jeanette Lin from UCLA, aiming to make the application experience equitable for fellows and programs, as well as to share ideas about how to successfully structure, fund and develop fellowship programs. The 2016 ACHD Guidelines should be published in the fall. The Adult Congenital Heart Association is launching ACHD program accreditation, with the initial 5 pilot sites having completed the process, and the first round of open applications starting in July 2016. Busy times in ACHD in the US!

Fellowships
By Jouke Bokma

The International Society of Adult Congenital Heart Disease (ISACHD) wishes to better understand the specific needs of ACHD and wishes to address those needs through involvement of fellows in the ISACHD community.

We want to further involve worldwide ACHD fellows in research and ISACHD activities. For this reason we are trying to extent our database of worldwide ACHD fellows. We are planning to survey fellows on
methods of learning/training and communicating. The results of this survey may help programs to adopt their programs to fellows needs. We have previously received contact information of many fellows in ACHD through by program leaders. However, we are still missing contact information of many ACHD fellows worldwide, especially from non-US countries.

*For all worldwide ACHD program leaders:* could you please inform us with email addresses of your institutions current and future clinical and research fellows in ACHD? We would also like to receive information on adult/pediatric cardiology fellows with an interest in ACHD.

Of course, fellows are free to decline participation in future activities themselves and may opt-out if they don't want to receive future e-mails. In addition, fellows themselves can also contact us direct if they want to be further involved in ISACHD.

Jouke Bokma, fellow-in-training representative  
j.p.bokma@amc.uva.nl

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**Global Health Working Group Update:**

*By Disty Pearson*

The Global Health Working Group reports success in engaging with ACHD providers in low and middle income countries (LMIC) across the globe. We recognize these are small steps to date and look forward to a more robust role in the future.

We continue to work closely with the International Quality Improvement Collaborative for Congenital Heart Surgery in Developing World Countries (IQIC). I was able to observe the congenital cardiac surgical programs in Mexico City and Guatemala City. We then attended the Latin American Learning Session in Bogota Columbia at which we had the opportunity to speak on ACHD care in a full session devoted to such. This was the first such session dedicated to ACHD care within the IQIC learning sessions underlying the importance given to the adult patient in LMIC. Each center we visited expressed enthusiasm for expanding into the care of ACHD patients and we have developed collaborations with local providers. Amy Verstappen then attended the Learning Session in Kerala India with IQIC, Children's Heart link and CHD providers from India and surrounding nations. In those sessions the importance of patient engagement was stressed and well received. Clearly IQIC and its more than 40 members in more than 20 LMIC is not only the strongest partner the working group has, but also a tremendous resource for providers around the world who are increasing their care of the ACHD survivor.

We continue our research; Global ACCESS (Adult Congenital Cardiac Needs Evaluation Systems) pilot program in Pakistan with our collaborators there led by Dr. Babar Hasan and Laila Ladak, RN. The Pakistan Ethics Review Board has approved the project and we are underway. The objectives for this project were reviewed in the March update, but briefly we are looking at the burden of ACHD care, spectrum of procedures currently performed as well as the perceptions of the need for ACHD care among providers and patients.

The Global Health Working Group continues to work on the International ACHD Program Survey and Directory, which has now contacted over 100 centers. We are working on this project with Adrienne Kovacs membership chair and Jouke Bokma fellow-in-training representative. There has been tremendous progress with the posting of the fellowship programs on the website and we look forward to a similar posting of ACHD programs soon. We again reach out to all ISACHD members who are in touch with programs worldwide to contact us with their information so that we may reach out to them to ensure they are included.
Working Group on Education

By Els Pieper

The main activity of the working group is the ACHD learning center (found on www.achdlearningcenter.org) which is blossoming under the leadership of Gary Webb.

The 15 minute module section has been expanding gradually as more presentations have been finished and posted. The cardiology fellows test center offers the possibility to make an account for your center, your fellows can login in your own user group with a personal account, follow the 15-minute modules and take the MCQ-tests related to the modules. We suggested 2 sets of modules most suitable for pediatric and adult cardiology trainees. Participating centers can also use their own set of modules as they consider appropriate. The resource is increasingly used. We have reviewed the test results and based on the scoring rates we have selected tests that are being reviewed and improved.

The most valued and used resource on the ACHD learning center is the Journal Watch which allows you to keep up to date with the least possible effort.

We are eager to hear your feed-back on the learning center, and your suggestions for further improvement are highly valued. To give feed-back or to be more actively involved, please contact Gary Webb or Els Pieper (Gary.Webb@chmc.org or p.g.pieper@umcg.nl).

The Working Group on Education has endorsed several meetings:

The 12th DHZB Lange symposium, September 16-17, Berlin;
Conference 'Adult Congenital Heart Disease in the 21th Century, Sept 23, Washington.

Working Group on 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:

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:

- 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 method.Int J Cardiol 2015;179:334-42.
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].

- **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. As of February 2016, 177 adults with CHD using NOACs have been enrolled from 37 participating centers worldwide. The inclusion will continue until at least 200 patients are enrolled 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](mailto:h.yang@amc.uva.nl)).

- **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](mailto:Laila.ladak@aku.edu)).

- **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](mailto: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 Aboulhosn, MD ([jaboulhosn@mednet.ucla.edu](mailto:jaboulhosn@mednet.ucla.edu)) if you would like to propose a multi-national research protocol or get further information.

**ISACHD Endorsed Meetings**

- **12th DHZB Lange Symposium, September 17-18, 2016, Berlin, Germany**

- **Adult Congenital Heart Disease in the 21st Century, September 23, 2016, Omni Shoreham Hotel, Washington, DC** ([PDF flyer](#))
• 10th Advanced Symposium on Congenital Heart Disease in Adult, 26th - 27th September 2016, Royal College of Surgeons of England, London, WC2A 3PE

• ISACHD is organizing the adult congenital heart disease content for the World Congress of Pediatric Cardiology and Cardiac Surgery 2017. The 7th World Congress of Pediatric Cardiology and Cardiac Surgery, scheduled July 16-21, 2017 will relocate from Istanbul, Turkey to Barcelona, Spain*

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.

*If you would like to discontinue receiving the ISACHD newsletter, please click here to unsubscribe.