Dear Friends,

With the holiday season upon us, it is a fitting time to reflect upon ISACHD's achievements and challenges. It is also an opportunity to thank you, our ISACHD members. In big ways and small ways, you are changing lives in our ACHD communities and are shaping our field in the process. Collectively, as a global society fueled by your energy and service, ISACHD is well positioned to pursue our overarching objective of achieving excellence in the care of adults with congenital heart disease across the world.

At our lively biannual meeting last month in Chicago, we discussed ways to strengthen ISACHD's organizational structure, fortify its membership, and enhance its global impact. Updates were provided by the executive committee, chairs of global health, education, and research working groups, cardiac care associates representative, and regional representatives from the U.S., Canada, Europe, Asia-Pacific, and South America. Progress was discussed on our first position statement entitled, "Where does ACHD care need to be in 10 years and how will we get there?". A presentation followed on the effect and safety of anticoagulation in ACHD, courtesy of Drs. Hayang Yang and Barbara Mulder from the Netherlands. This led to the introduction of a new research project, the NOTE registry, which aims to assess the efficacy and safety of NOACs in ACHD. Please refer to the update below for further details, including contact information to participate.

The ISACHD meeting culminated with the inaugural lifetime achievement award, presented posthumously to Dr. Joseph K. Perloff, a visionary, teacher extraordinaire, exemplary clinician, and a founder of our field. I encourage you to peruse the slides from Dr. Jamil AboulHosn's touching testimony of Dr. Perloff's life and career [http://isachd.org/sites/default/files/sites/default/files/perlof.pdf]. Benjamin Lempert, Dr. Perloff's grandson, accepted the award on behalf of the Perloff family.
I very much look forward to pursuing our objectives together in 2015 and wish you and yours a healthy and prosperous new year!

Sincerely,

Paul Khairy, MD, PhD
ISACHD President

Regional News

News from Asia-Pacific

By Clare O’Donnell

The Asia Pacific group incorporates a variety of member countries including some with strong traditions of ACHD care (eg Japanese Society for Adult Congenital Heart Disease) and others just in the early stages of development of their programs. We face varied challenges - in some settings the majority of patients have unpalliated or unoperated disease and in other countries our ACHD patients are reaching more advanced ages bringing great encouragement but also new challenges.

The 2014 regional gatherings included the Asia Pacific Society of Adult Congenital Heart Disease sessions in New Delhi and an ISACHD sponsored session "ACHD- an update for the General cardiologist" at World Heart Federation Meeting in Melbourne, May 2014.

Upcoming Meetings in 2015 include Japanese Society for Adult Congenital Heart Disease January 16-18 in Tokyo. Interventional approaches in adult congenital heart disease will be part of the PICS-AICS Asia Pacific 2015 (April, Taipei) and CSI Asia-Pacific 2015 (March, Ho Chi Minh City) meetings.
News from South-America
By Amalia Elizari

The 40th Argentinian Congress of Cardiology will be held in Buenos Aires from October 15 to 18. During this Congress, it will be decided of which CHD (Congenital Heart Disease) in South America will be in charge of gathering an information about the population of adult and pediatric patients bearing different congenital heart defects.

European News
By Els Pieper

From 15th to 18th october 2014 the 9th Echocardiography in Congenital Heart Disease course was held in Timisoara, Romania. These yearly courses allways attract a large number of attendants, both physicians and echocardiographers, with either a pediatric or adult congenital cardiology background. The courses prepare for the accreditation exam for Congenital Heart Disease Echocardiography organised by the European Association of Echocardiography and the Association for European Pediatric and Congenital Cardiology. An increasing number of pediatric and adult cardiologists and echocardiographers is pursuing accreditation. This year nearly 100 people sat the exam at the EuroEcho Congress in December in Vienna.

A meeting to look forward to is the 6th EuroGuch meeting, which is organized on behalf of the GUCH working group of the ESC at Friday / Saturday 8th / 9th May 2015 in London. The focus will be on innovative treatments and interventions.

Research Working Group
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 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 will be completed by December 31st, 2014. As of September 2014, five centers had completed data collection and more than 2,800 patients had been enrolled. The estimated total sample will be 3,500-4,000 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. The methods paper describing the rationale, design, and methods of APPROACH-IS is ready for submission. Substudies 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. JOIN the NOAC registry !!
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) or Barbara Mulder (b.j.mulder@amc.nl)

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) if you would like to propose a multi-national research protocol or get further information.

Global Health Working Group News:
By Disty Pearson

The working group continues to work to: promote lifelong care of the congenital heart patient worldwide that is sustainable, and culturally and socially sensitive. We have developed a two pronged approach. To look at the larger picture of ACHD care in developing countries from a global public health perspective. We are in the process of creating an advisory council to inform this discussion. To date confirmed members are: Aldo Castaneda, Curt Daniels, Francis Fynn-Thompson, Paul Khairy and Clare O'Donnell.

We are also working to create databases of Cardiac Societies, and CHD medical providers in the "developing world" caring for ACHD'ers. These will be primarily pediatric cardiac surgeons/cardiologists who have medical missions to the developing world and will carry the message that CHD patients need life long care. Also, a data base of ACHD centers in the "developed world" willing to participate in partnerships with developing countries and provide support and potential "Twinning" relationships.

If you know of medical missions and/or you are willing to discuss partnering with providers in the developing world please contact me.

Thank you!

Working Group on Education
By Els Pieper

Our main recent activities centered around endorsement of meetings under the lead of Gruschen Veldtman and further development of the ACHD learning center led by Gary Webb.

Endorsement of Meetings

The working group endorsed the past months the 9th advanced symposium on CHD in the Adult, which was held in London, Sept 29-30 2014; the basic course on congenital and paediatric echocardiography in Toronto, Nov 28-30 2014; and the 115th DZHB Lange Symposium which this year concentrated on pulmonary atresia, Connecting Heart and Lung, and which will take place in Berlin, Jan 17-18 2015. We endorse meetings with high quality scientific content and offer announcement of the meeting through the website and newsletter, while we require a discount for ISACHD members and our logo to be placed on the flyer of the meeting. Any requests for endorsement of a meeting can be sent to p.g.pieper@umcg.nl

ACHD Learning Center and CHiP Network

The ACHD learning center and CHiP network are led by Gary Webb. The ACHD learning center aims to bring together educational resources of all types for ACHD professionals and cardiology trainees.

The learning center was officially launched in October. The site can be found at www.achdlearningcenter.org. It contains a large and ever growing amount of valuable information that helps to keep your own knowledge up to date and that has great value as teaching material.
After spreading the news of the official launch of the learning center, in about 20 days the site was visited more than 2000 times, an average of over 100 times daily with peaks in the first 10 days. More than 70% were new visitors. New resources on the site are the presentations from the 2012 Toronto meeting and the CHD Journal watch, which is monthly communicated through the CHiP network and the ISACHD website and is housed on the ACHD learning center;

Editor of this JW is Dr Patel and there are subeditors for the different subsections. The Journal watch lists the papers that have been published in the different areas of interest and the editors highlight several papers each month.

The collection of cardiology fellow lectures is growing steadily. Thirty lectures are now on the site and we aim for 55. The lectures will together constitute a comprehensive basic course in adult congenital cardiology, suitable for cardiology trainees and fellows. Our invited faculty consists of experts in the field of ACHD. All lectures are reviewed by 2 members of the Educational Board of the ACHD Learning Center and edited when necessary. These are short lectures, on average 15 minutes, which is an optimal duration for web-based learning. We will encourage directors of clinical congenital heart disease programs to incorporate the course in their educational program. For this purpose we are setting up a formal education for cardiology trainees all around the English-speaking world, with MCQ's that will be communicated through a secure testing site that is available through Cincinnati Children's Hospital. We also aim to send out monthly messages about featured content on the Learning Center.

The working group is very grateful for the contributions of lecturers of the fellow course, and our special thanks are to Cincinnati Children's Hospital for their sponsoring.

We invite you to go to www.achdlearningcenter.org and look around! Any suggestions for content that we can link to or place on the website can be sent to Gary Webb or myself (p.g.pieper@umcg.nl)

CCA News

New efforts are being made to meet the needs of ISACHD CCA members. We are currently looking to identify CCA Members to serve as regional representatives and to serve on a nursing education work group. Responsibilities as regional representative would include submitting quarterly updates from your region and identifying individuals from your area who would be interested in being part of ISACHD. Participation in the nursing education work group would require involvement in conference calls every month or every other month, sharing of clinical experience, and helping to write educational material. If you are interested, please send an email to Sue Fernandes at Sfernandes@stanford.edu. Please place ISACHD CCA in subject line.

The ISACHD Fellow Survey

The ISACHD board aims at getting involvement of more fellows in ISACHD. We are conducting an online survey to gain better understanding in current fellows training and experiences as well as how to get more fellows involved in ISACHD. Pediatric or cardiology fellows with interest in ACHD, ACHD fellows, as well as research fellows are welcome to participate in this survey. The survey will take approximately 15-30 minutes to complete. Fellows who wish to participate in the survey can contact Jouke Bokma (j.p.bokma@amc.uva.nl). In addition, ACHD program leaders are asked to provide contact information of current fellows who may wish to participate.

Journal Watch

The journal watch section on the ISACHD website is now divided in two different sections. Firstly, the general section links to the extensive journal scan on adult congenital heart disease provided by the ACHD learning center. Secondly, in the 'specially featured articles section selected ACHD articles are highlighted. This section includes short comments by Gruschen Veldtman and Jouke Bokma on the highlighted articles. ISACHD members that wish to contribute to this section are welcome to provide suggestions for articles and comments.