Dear ISACHD Members,

As the updates in this newsletter from our various working group chairs and representatives attest, ISACHD continues to make strides in advancing its mission of promoting, pursuing, and maintaining excellence in the care of adults with congenital heart disease (ACHD) on many fronts.

To highlight a few achievements, our international APPROACH-IS study, i.e., Assessment of Patterns of Patient-Reported Outcomes in ACHD-International Study, has enrolled over 2800 subjects from 16 countries. It has become, no doubt, one of the largest prospective studies ever conducted in ACHD. Our Global Education Working Group, in collaboration with Cincinnati Children's Hospital Medical Center, has assembled an impressive collection of online ACHD lectures within an ACHD modular learning course. These may be accessed through our website (www.isachd.org) by clicking on the "ACHD Learning Center" tab. ISACHD is also intensifying its efforts to reach out to and better serve the needs of all valued members of our ACHD teams, including ACHD fellows, nurses, advanced practice providers, and mental health professionals.

We very much look forward to discussing these and other initiatives with you at our upcoming meeting during the American Heart Association Scientific Sessions in Chicago. In addition to the updates and project discussions with our new executive, representatives, and chairs, the meeting will feature the presentation of ISACHD’s first annual Lifetime Achievement Award! Tentative details regarding our meeting are summarized below:

Date: Sunday, November 16, 2014
Time: 7:00 - 9:30 PM
Place: Chicago Room, Palmer House Hilton, 17 East Monroe Street,
Chicago, Illinois, 60603, USA
Agenda:

19:00 Cocktails, appetizers, and networking

19:20 Welcome- Paul Khairy (President)

19:30 Updates from the ISACHD executive

- Membership and treasurer's report- Adrienne Kovacs (Treasurer)
- Cardiac care associates: Susan Fernandes (CCA Representative)

20:00 Working group updates

- Global Education- Els Pieper (Chair, Global Education Working Group)
- Global Health Care- Disty Pearson (Chair, Global Health Care Working Group)
- Global Research- Jamil Aboulhosn (Chair, Global Research Working Group)

20:45 Regional updates (Europe, South America, Asian-Pacific, USA, Canada)

21:00 ISACHD Lifetime Achievement Award

21:25 Wrap-up and next steps- Paul Khairy and Erwin Oechslin (President-Elect)

We very much look forward to the opportunity to gather with you and our colleagues from around the world for some food, drinks, and exchanges. Please join us!

Paul Khairy, MD, PhD
ISACHD President

Regional News

News from Asia-Pacific

By Clare O'Donnell

This year in May, the ISACHD sponsored a session at the World Heart Federation Meeting in Melbourne, entitled "Adult Congenital Heart Disease - an update for the General Cardiologist". Talks were given by Tim Hornung, David Celermajer and Clare O'Donnell on topics including Imaging in ACHD, intervention in ACHD, and Pulmonary hypertension in ACHD, and also, Geoff Strange presented a paper based on the date from the Australia/New Zealand ACHD-PAH registry. A formal plan was also made to encourage attendees to join ISACHD and participate in its global aims, which we hope had already bearing fruit!
During other sessions of the meeting, particularly in the pediatric/congenital stream, there were reflections on the global challenges of ACHD care, including papers from Dr Craig Sable, on addressing the needs of patients with un-repaired congenital heart disease in sub-Saharan Africa, and a thought of provoking a paper from Dr Krishna Kumar from India, entitled 'Alternative models for taking care of adults with congenital heart disease'.

**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 and Barbara Mulder*

From August 30th to September 3rd, the ESC congress was held in Barcelona, Spain, and attracted over 30,300 delegates. Besides many ACHD sessions during the entire conference, a joint ISACHD-ESC meeting was organized on Sunday afternoon, with excellent speakers on innovative interventions in ACHD. The session was cheerfully chaired by Gary Webb and Helmut Baumgartner. Our ISACHD president Paul Khairy himself gave an excellent talk on Electrophysiological devices in ACHD: pacemakers, defibrillators, and beyond... Andrew Taylor gave insight in future MRI guided interventions, John Pepper showed the London results of external wraps for aortic root surgery, and Andreas Eicken gave his thoughts about the future of transcatheter pulmonary valve therapy. Afterwards, we could enjoy a wonderful social event with drinks and Spanish food at the Museum Nacional d'Art de Catalunya in Parc Montjuic. Next year, the ESC congress will be held in London.

**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 research working group was formed in July of 2014. We are pleased to announce the following membership: Sue Fernandes, Paul Khairy, Jolien Roos-Hesselink, Philip Moons, Clare O'Donnell, Francois Pierre Mongeon, Gruschen Veldtman, Barbara Mulder and Jamil Aboulhosn.

The first such project to be endorsed by ISACHD research working group 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 in the process of reviewing multiple multi-national research projects and we are looking for additional multi-national studies to review and potentially endorse. Please contact the working group chairperson, Jamil Aboulhosn, MD (jaboulhosn@mednet.ucla.edu), if you would like to propose a multi-national research protocol or get further information.

NOTE-registry
NOACs in ACHD? The NOTE registry will evaluate its safety. In the NOTE registry adult CHD patients are followed using NOACs for thromboembolic prevention in atrial arrhythmias. This multicenter registry is currently recruiting in 6 European countries. We are looking for more participating sites worldwide; All centers are invited to join and include ACHD patients using or starting NOACs. For further information on the protocol and to obtain the CRF, please get in touch with one of the research fellows: Hayang Yang, h.y.yang@amc.nl Josephine Heidendael, j.f.heidendael@amc.nl On behalf of Prof. Barbara Mulder, Academic Medical Center, Amsterdam, The Netherlands. (b.j.mulder@amc.nl)

Recognizing the Value of All Members of the ACHD Team
By Sue Fernandes

A team-based approach is essential to ensure patient-centered care for complex patient populations. The type of team necessary to provide high quality patient-centered care and the resources required for such a team depend, in part, on the complexity of the underlying disease and additional co-morbidities.1

In few fields is the need for team-based care more evident than adult congenital heart disease (ACHD). As this population continues to grow steadily, we are seeing a shift toward a greater percentage of patients with moderate and complex forms of congenital heart disease (CHD).2 For the first time in history, large numbers of patients with moderate and complex CHD are reaching their 5th, 6th and even 7th decade of life. This improved survival allows these patients to live long enough to be
impacted by adult co-morbidities such as acquired heart disease, diabetes, and cancer. Considering the many facets of care for ACHD patients, it is clear that the type of team required to optimize outcomes must be comprehensive, empowered by the resources necessary to ensure a high quality patient-centered approach.

The idea of the lone ACHD cardiologist is becoming obsolete. The indispensable role that advanced practice providers (APPs) including clinical nurse specialists, nurse practitioners, and physician assistants, along with nurses, social workers, and psychologists play in the day-to-day care of ACHD patients is increasingly recognized. Adults with CHD consume substantial healthcare resources, as reflected by the high number of outpatient visits, emergency room visits, and days of hospitalization. Many ACHD physicians today partner with APPs to meet the increasing need for health care access in the inpatient and outpatient settings. While APPs are licensed and credentialed for a higher level of direct patient care, the utilization of an office nurse coordinator in ACHD centers has not been fully examined, but is rapidly becoming recognized as an integral part of a busy ACHD practice. An ACHD nurse coordinator can triage daily phone calls, maintain phone surveillance of high risk patients, act as a clinical liaison and facilitator for insurance utilization if applicable, order and track testing, coordinate care with sub specialists, and provide ongoing patient education appropriate to changing clinical situations. In addition, ACHD patients frequently require psychosocial or emotional support, much of which can be provided by the ACHD nurse coordinator and APPs, although advanced psychosocial assessment should ideally be provided by individuals with expertise in mental health, such as social workers or psychologists. The role that these mental health professionals play in ACHD care is vital. To ensure access to this type of high quality, patient-centered ACHD care, it is essential that we embrace a team-based approach, recognize the value that each member brings to the team and provide a venue for fostering multidisciplinary education, research and collaboration.

At ISACHD, we value the ACHD team and all of its members. We strive to be the organization that physicians, cardiology fellows, nurses, APPs, and mental health professionals turn to in the pursuit of promoting, maintaining and pursuing excellence in ACHD care worldwide. In the near future, we hope that you will see an increasing visibility of the value we place on the ACHD team-based approach. Some of the initiatives under consideration include: adding working groups to meet the educational needs of nurses, APPs and mental health professionals; expanding regional representation to include non-physician members of the ACHD Team, including publications relevant to all members of the ACHD team in the ISACHD Journal Watch, and encouraging greater participation and leadership by nurses, APPs and mental health professionals within ISACHD. Importantly, we welcome your input on how ISACHD may best serve all caregivers within the ACHD team. Please follow this link to provide us with anonymous comments: www.surveymonkey.com/s/ISACHDTBC7FMB3MK. We
look forward to hearing from you!

Journal Watch

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