

June, 2013

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International Society for  
Adult Congenital Heart Disease

[In This Issue](#)

[Regional News](#)

[Journal Watch](#)

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## ISACHD Newsletter

### President's Message



by Curt J Daniels

Dear ISACHD Members,  
The 23rd International Symposium on Congenital Heart Disease in the Adult, this past month in Skamania, Washington, USA, met and exceeded expectations once again; a beautiful venue, outstanding presentations and a state of the art educational experience. Congratulations to Course Directors Craig Broberg, David Sahn, Karen Stout, Erwin Oechslin, and Gary Webb. The pre-meeting for ACHD CCAs was well attended and highlighted the important role of the CCAs in ACHD patient care and program development. The meeting provided a great mix of basic ACHD evaluation and management for those new

to the specialty but also robust up-to-date research, education and debate on some of the most difficult issues facing ACHD patients. We look forward to the 24th edition in Cincinnati OH, USA next June 2014.

ISACHD continues to move forward with several Global Initiatives.

ISACHD Global Health Care work group has formally submitted a proposal to an international health organization to partner for the development of ACHD programming in underserved countries. Currently, the WG is pursuing funding and a more detailed plan to include training, and on-site and eLearning education. More to come.

ISACHD Global Education Work Group (Chair Erwin Oechslin, MD Toronto, Canada) continues its work to develop the **ACHD eLearning Center**, lead by Gary Webb, MD (Cincinnati, USA). Work is being done to develop an ACHD basic teaching course and a repository for online ACHD education. This initiative fits nicely with the Global Health agenda to support the educational development of international ACHD programs.

The Global Research Work Group has initiated a new international multi-center study entitled Assessment of Patient-Reported Outcomes in Adults with Congenital Heart Disease - International Study (APPROACH-IS). The study design has been developed and is coordinated by Philip Moons, PhD, Koen Luyckx, Silke Apers, (Leuven, Belgium), and Adrienne Kovacs, PhD. The study utilizes a number of patient surveys to assess international differences in perceived health, psychosocial functioning, behavioral outcomes and quality of life. Sites interested in participating please contact Philip Moons. Several centers are on-board to begin recruiting patients.

ISACHD continues to move forward its agenda for improving ACHD Global Health, Global Education, and Global Research. Please join ISACHD, become a member and contribute to the work and the effort to improve ACHD care, education and research around the world.

Please visit our website at [www.isachd.org](http://www.isachd.org) to learn more about ISACHD, visit the journal watch page and find the latest ACHD publications, view upcoming conferences endorsed by ISACHD and register to become a member of ISACHD. Look forward to seeing you soon,  
Curt J Daniels, MD, President

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

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## Regional News

### News from USA



The 23rd International Symposium on Congenital Heart Disease in the Adult Skamania June 1-5, 2013,

*by Barbara Mulder*

Course directors:

Craig Broberg, MD (Oregon Health & Science University)

Karen Stout, MD (University of Washington)

David Sahn, MD (Oregon Health & Science University)

Gary Webb, MD (Cincinnati Children's Hospital)

Erwin Oechslin, MD (University of Toronto)

The Skamania meeting was a great success again. The weather was beautiful, which allowed for a frequent outdoor coffee or tea and terrific views from the terrace! The 200 attendees spent 5 days together; great sessions and high level talks resulted in fully crowded meeting rooms.

Saturday afternoon pre-sessions included an ACHD cardiac care associate conference and a basic introduction of ACHD. The pre-sessions ended with a reception in the sunny garden.

Contemporary reviews at Sunday morning included superb lectures from outstanding experts in the field. During breakout sessions on aorta pathology and shunts, research and program building a spectrum of diverse topics was addressed. No rest during dinner: an overview of ACHD history and an exciting ACHD trivia competition. The Swiss table surprisingly won, although questions were mostly related to American themes.

After an interesting session on TGA on Monday morning, the first hilarious debate was held between our ISACHD president Curt Daniels and Brian Kogon on children's versus adult facilities, followed by Anne Valente and Isabelle Vondermuhl on the use of late gadolinium enhancement with MRI. All speakers appeared to be winners, as arguments were very strong on both sides.

The traditional afternoon hikes were exciting with the beautiful weather and a full week of showers before. The falls were overwhelming and the brave guides had to take care of a large crowd, who needed to sign a waiver for taking own responsibility on the trip. No accidents happened and we could all join the Sternwheeler dinner cruise on the Columbia River. Although a beautiful and large river, the Nile has been determined to be the largest river in the world followed by the Amazon and the Yangtze. Still, our dinner cruise with beautiful sunset was wonderful, quiet and peaceful, without any inappropriate row from the captain's hut. Craig took care of surveillance measures in place to protect against unauthorized access to the Sternwheeler PA system. Of course, the day couldn't end without the David Sahn memorial campfire songfest, bringing back the sixties, with guitars and loud singing.

Fontan, arrhythmias, pulmonary hypertension and cases filled a scientifically worthwhile Tuesday. Wednesday morning ended with the Best Research Awards presentation and two more exciting debates. Craig stirred up the audience by quoting a previous email conversation between the debaters. Because Jack was afraid of going to be killed in the debate, he had written: "So if this is my swan song, it's been great knowing you all."

We have to acknowledge and thank the organizers for such a fantastic meeting!



### News from Asia



*by Koichiro Niwa*

The 8th ACHD seminar took place in Tokyo, June 15-16, 2013  
(<http://www.jsachd.org/>)

The 4th Congress of Asia-Pacific ACHD Society will be held in New Delhi, India, March, 2014.

Call for abstracts will be announced soon.

### News from Canada



*By Ervin Oechslin, Toronto (Canada)*

#### **ACHD Training Guidelines**

The CACH Network Board submitted the topic of CCS/CACH Network Guidelines for Physician Training and Maintenance of Competency in ACHD - Position Statement and Recommendations and Recommendations of the Canadian Adult Congenital Heart Disease Network Census Panel - for the CCS 2013 call for guideline and position statement topics in February 2013. We received the decision letter in May 2013: 13 topics were submitted, but our proposal was not among the two selected topics of the Guidelines Committee of the CCS. We evaluate the process to submit a request to the Royal College of Physicians and Surgeons of Canada (RCPSC) because our proposed topic seems to be more suited for the Training and Maintenance of Competence Standards.

#### **Inaugural Joint CCS/ESC Session to Focus on ACHD**

The Canadian Cardiovascular Society (CCS) has been a European Society of Cardiology (ESC) affiliate since 2010 and benefits from specific offers of the ESC family. We are proud that CACH Network was asked to organize the Inaugural Joint CCS/ESC Session at the ESC Congress in Amsterdam (NL). The session

entitled Challenges in ACHD care - future considerations will be held on Monday, September 2, 2013, 8:30 am to 10:00 am.

The following presentations are scheduled:

- The fate of survivors with complex congenital heart disease: implications for ACHD clinics? - M. Greutmann, Zurich (CH)
- Sudden cardiac death: does risk stratification work? - L. Harris, Toronto (CA)
- Discrete subaortic stenosis - reconsidering the guidelines? - JW Roos-Hesselink, Rotterdam (NL)
- Quality measures in ACHD: what are they and how can we use them? - A. Marelli, Montreal (CA)

Information and program of the ESC Congress 2013 in Amsterdam is available at [www.cachnet.ca](http://www.cachnet.ca) or at <http://www.escardio.org/congresses/esc-2013/Pages/welcome.aspx>

### **CACH Network Newsletter**

An e-Newsletter under the leadership of Dr. Jasmine Grewal, Vancouver (BC) was just published 10 days ago. This newsletter will facilitate communication and exchange of information among the 15 centres in Canada, allow us to present updates of the CACH Network centres from East to West, to highlight research, and to provide updates for the Nurses/Nurse Practitioners amongst other topics. Please access the newsletter at [www.cachnet.ca](http://www.cachnet.ca) or <http://www.cachnet.org/downloads/2013-06-CACHNetworkNewsletter.pdf> Please visit [www.cachnet.ca](http://www.cachnet.ca), access 'Resources' to download international guidelines and the glossary amongst others, and read the President's message for more information.

Erwin Oechslin,  
President, CACH Network

### **WG on Education**

*By Ervin Oechslin, Toronto (Canada)*

### **ACHD e-Learning Center**

The ACHD e-Learning Centre is making progress! The Editorial Board of the ACHD e-Learning Center (Chair: Dr. Gary Webb, Cincinnati) has discussed the development and progress of the Website during Conference Calls, and has already identified high quality education material, which will be posted on the Website. The Cincinnati Children's hospital provides financial and logistic support and IT expertise to establish this Website under the guidance and directions of the Editorial Board. The Website is supposed to go live in the Fall 2013.

Basic Teaching Course in ACHD: This online course, targeting trainees in adult cardiology, is organized under the leadership of Dr. E. Pieper, Groningen (NL). The invited speakers are submitting their presentations (15 minutes each) in these days.

Case Presentations in ACHD: Dr. Richard Krasuski (Cleveland) and Dr. Simran Singh (New York) are putting together a program for case based teaching, with focus on interventional cases. These case presentations, however, will focus on hemodynamic aspects and indications for interventions. Technical aspects of the procedures are not the scope of this case based teaching program.

I am very grateful to the Editorial Board Members and to Dr. Gary Webb, Dr. Richard Krasuski, Dr. Simran Singh, Dr. Els Pieper, and to all presenters at the basic teaching course in ACHD in particular for the progress of our projects.



## **The ACHD e-Learning Center will be an e-hub for educational resources in ACHD!**

### Editorial Board Members of the ACHD e-Learning Center:

Gary Webb (Chair of the Editorial Board, moderator), Teliji Akagi (Japan), Naser Ammash (USA), Helmut Baumgartner (DE), David Drajpuch (USA), Kate English (UK), Richard Krasuski (USA), Philip Moons (BE), Erwin Oechslin (CA), Els Pieper (NL), Harsimran Singh (USA), Jonathan Windram (CA).

### Endorsement of ACHD Meetings

There is no upcoming meeting which is endorsed by ISACHD. Please be proactive and contact me at [erwin.oechslin@uhn.ca](mailto:erwin.oechslin@uhn.ca) if you want to endorse your ACHD meeting or if you are aware of a meeting which should be endorsed by ISACHD.

Erwin Oechslin, Toronto  
Chair, WG on Education

### **WG on Education**

*By Ervin Oechslin, Toronto (Canada)*

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Erwin Oechslin, Toronto  
Chair, WG on Education

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## **Commentary on the article "Quality of life of adult congenital heart disease patients: a systematic review of the literature" by Silke Apers**

Fteropoulli and colleagues conducted a systematic review of the literature including 31 quantitative studies on quality of life (QOL) in adults with congenital heart disease (CHD). The objectives of this study were: (1) to describe QOL in adults with CHD; (2) to examine the relationship between disease severity variables and QOL; (3) to identify the quality of the literature; and (4) to formulate directions for future research. In total, seven electronic databases were searched. All relevant studies published in English until November, 2011 were included in this systematic review.

### **1. Quality of life in adults with congenital heart disease**

Both generic (e.g., SF-36) and disease-specific (e.g., CHD-TAAQOL) measures of QOL were used in the included studies. With regard to physical domains of QOL, most studies (20 out of 26 studies) reported a reduced QOL in patients with CHD. Conversely, the majority of studies evaluating psychosocial (21 out of 24 studies) and environmental or occupational domains of QOL (4 out of 6 studies) found no differences between patients and controls. The studies included in this review consistently reported that a worse QOL was associated with younger age and female sex.

### **2. Disease severity variables and quality of life**

Findings with regard to the association between QOL and cyanosis, exercise capacity, and functional status were inconsistent. Moreover, mixed results were found with regard to the association between disease severity, which was categorized in different ways, and QOL.

### **3. Quality of the literature**

In general, the included studies have contradictory findings, possibly resulting from limitations in study methodology. Common methodological shortcomings were: small sample sizes, cross-sectional study designs, and not distinguishing between different diagnostic groups of CHD. Furthermore, the authors criticized one very important shortcoming of the included studies, namely the lack of a clear conceptual background. Indeed, there is no consensus on the definition of QOL and its measurement. As a result, the instruments used to measure QOL in the included studies varied greatly.

### **4. Areas for future research**

Future studies should include larger samples, apply longitudinal research designs, use sound conceptualization and measurement of QOL, and find consensus with regard to disease severity classification.

To summarize, the current body of knowledge does not provide conclusive evidence on QOL in adults with CHD and, furthermore, does not allow for designing prevention or intervention programs that boost QOL. First, the fact that most studies use a cross-sectional design makes it impossible to conclude on temporal sequences and the direction of effects. This is, however, crucial for the design of effective interventions. Second, we still need to know more about QOL in adults with CHD and gain in-depth understanding of its modifiable

determinants, such as certain personality characteristics [1;2] or a sense of coherence [3]. To date, only one longitudinal study in the field of CHD has been published that examined the direction of effects between QOL and potential determinants. This study indicated that perceived health, parental support, and sense of coherence predict changes in QOL over time in adolescents with CHD [4].

In conclusion, the biggest challenge related to QOL research in the field of CHD is to find conceptual and methodological consensus and, subsequently, to move on from observational studies to interventional research.

[1] Schoormans D, Mulder BJ, van Melle JP, Pieper EG, van Dijk AP, Sieswerda GJ, Hulsbergen-Zwarts MS, Plokker TH, Brunninkhuis LG, Vliegen HW, Sprangers MA. Patients with a congenital heart defect and type D personality feel functionally more impaired, report a poorer health status and quality of life, but use less healthcare. *Eur J Cardiovasc Nurs* 2012, 11: 349-355.

[2] Rassart J, Luyckx K, Klimstra T, Moons P. The importance of studying personality in individuals with congenital heart disease. *Eur J Cardiovasc Nurs* 2012, 11: 261-262.

[3] Müller J, Hess J, Hager A. Sense of coherence, rather than exercise capacity, is the stronger predictor to obtain health-related quality of life in adults with congenital heart disease. *Eur J Prev Cardiol* 2013, DOI: 10.1177/2047487313481753.

[4] Luyckx K, Missotten L, Goossens E, Moons P. Individual and contextual determinants of quality of life in adolescents with congenital heart disease. *J Adolesc Health* 2012, 51: 122-128.

Article: Fteropoulli T, Stygall J, Cullen S, Deanfield J, Newman SP. Quality of life of adult congenital heart disease patients: a systematic review of the literature. *Cardiol Young*, 2013, DOI: 10.1017/S1047951112002351.

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