



International Society for
Adult Congenital Heart Disease

Five Year Vision

APRIL 2017

Based on mini-retreat and discussion at the semi-annual meeting in New Orleans in November 2016, and consultation with the entire ISACHD executive / regional representatives / Cardiac Care Associate and Fellow in-Training Representatives

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INTRODUCTION

The International Society for Adult Congenital Heart Disease (ISACHD) 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 Adult Congenital Heart Disease (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. The mission of ISACHD is to advance knowledge and training in medical disciplines pertinent to congenital heart disease in adults, to promote, maintain and pursue excellence in the care of ACHD worldwide; to bring together international health care providers interested in ACHD. **ISACHD is the United Nations of the ACHD community:** it is the umbrella organization through which health care providers can meet, interact and better understand each others' challenges and needs and successes.

The environment is changing! ISACHD must continue **finding and defining 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 must be different and must offer a product which isn't offered by other organizations.

ISACHD mailed a survey to seek input from all ACHD providers, researchers and trainees in order to help us set ISACHD priorities, know the expectations of the ACHD community and allocate resources accordingly. We have received feedback from more than 150 respondents including current and past ISACHD members, as well as from people who have never joined ISACHD.

The Executive Board 2016-2018, Past-Presidents, Cardiac Care Associate and Fellow-in Training Representatives, and Regional Representatives had a **Mini-Retreat** with an in-depth discussion and reflection about the global mission of ISACHD and priorities during the next five years. We dedicated three hours in New Orleans prior to our semi-annual meeting to reflect on our mission and how to best serve our members and patients. We shared the results of the Survey and outcome of the mini-retreat at the Semi-Annual Meeting in New Orleans and received important feedback from our members during a very constructive, lively.

This document, the product of the survey, mini-retreat and discussion at the semi-annual meeting in New Orleans in November 2016, summarizes the 5-year vision of ISACHD.

I express my sincere appreciation to all respondents who have completed the survey and provided their feedback. Their input and the feedback from the participants at the Semi-Annual meeting guided our discussion and decisions about future priorities. Participants of the mini-retreat deserve a special acknowledgement who dedicated their time to ISACHD and its future direction.

On behalf of the ISACHD Board



Erwin Oechslin, MD
President, ISACHD

Participants at the Mini-Retreat

Date: Sunday, November 13, 2016; 11 am to 2 pm CST

Location: Hampton Inn & Suites Hotel, 1201 Convention Center Blvd,
New Orleans, LA 70130

Board Members

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

Past President:

- Dr. Jack Colman (by conference call) President 2006-2008

Regional Representatives

- Dr. Ariane Marelli Montreal, Canada
- Dr. Karen Stout Washington, USA

Cardiac Care Associates Representative

- Susan M. Fernandes, LPD, CAP Paolo Alto, USA

Fellow-in Training Representative

- Dr. Jouke P. Bokma Amsterdam, NL

Key Conclusions and Action Items

I. ISACHD Priorities

Conclusions:

- To promote ISACHD's mission of global collaboration and to operationalize stakeholder involvement in ISACHD activities / the 3 domains of global education, global research and global health.
- To improve ISACHD infrastructure and to add value to the membership fee.

Action Items:

- To engage the ACHD community across the globe by improvement of the ISACHD infrastructure including the Website and development of a Member Portal / Discussion Forum (accessible for ISACHD members only).

II. Scientific and Business Meetings

Conclusion:

- To peel the perception off ISACHD being a North American Society.

Action Items:

- To engage regional representatives to implement the ISACHD mission of global presence.
- To have only one semi-annual meeting in North America (e.g. at the International Symposium on Adult Congenital Heart Disease).
- To have a second meeting on another continent (e.g. Europe, Asia, South America on a rotating schedule).

III. Research

Conclusion:

- ISACHD does not have the infrastructure and financial power to conduct research.

Action Item:

- To serve as a vehicle and facilitator for global, collaborative research.

IV. Newsletter

Conclusions:

- Global communication is the key to engage the ACHD community.
- Frequent Newsletters with a wealth of news may not be read.

Action Items:

- To publish two newsletters per year.
- To publish an intermittent Newsflash as needed.
- To communicate with members through a member portal (when available).

V. Journal Watch

Conclusion:

- To avoid duplication and overlap of the Journal Watch on ACHD (ISACHD and CHiP Network)

Action Item:

- To publish one ACHD Journal Watch in the CHiP Network in association with ISACHD and on the banner of ISACHD.

VI. Position Statements

Conclusion:

- To publish position statements with a global perspective and relevance, without duplication of already published guidelines.

Action Item:

- To implement a process about selection of the topics, invitation of the writing committee and review.

VII. ISACHD Website

Conclusion:

- To be the primary mode of communication and engagement of the ACHD community.

Action Item:

- To evaluate and to find options to improve the quality of the ISACHD Website.
- To develop a Member Portal so that ISACHD members can communicate and interact in a private and secure forum.

VIII. Membership Fees & Fundraising

Conclusion:

- To improve ISACHD infrastructure without significant increase in membership fees.

Action Items:

- To consider multiple strategies to secure finances in order to accomplish the mission of ISACHD (e.g. non-restricted education grants, donations).
- To increase the number of members by the provision of unique value for ISACHD members.

SURVEY SUMMARY – HIGHLIGHTS (Slides)

Highlights

- **Priorities:** Current ISACHD priorities/working groups (Education, Research, Global Health) were viewed as extremely important, as were connecting providers around the world and working with other ACHD organizations (ie, focus on collaboration)
- **Research:** Most respondents who had not participated in ISACHD-endorsed research did not know about the projects and/or that they were able to participate (ie, focus on communication)

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Highlights

- **Newsletters:** Almost all respondents favored continued widespread distribution (vs. distribution only to dues-paying members). Topic-based messages?
- **Journal watch:** Considered the most useful component of the newsletter (ISACHD now collaborates with the CHIP network)
- **Position statements:** Potential ideas were rated as very important; important to make these accessible

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Highlights

- **Meetings:** Important to expand out of North America!
- **Website:** Over 50% were in favor of having both public and private content; respondents supported most potential areas of improvement

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Highlights: Fees & Funding

- Most respondents are in favor of keeping the fees as they currently are (\$95 for physicians, \$65 for other providers, and \$35 for trainees)
- Some respondents commented on value for money
- Some respondents encouraged corporate sponsorship
- ~50% supported institutional membership but the fee/structure is unclear

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FUTURE DIRECTIONS

Future Directions

- **ISACHD Priorities**
 - Increase awareness of ISACHD's values as **GLOBAL** organisation for cardiovascular team members
 - Invite active participation of all CV team members across the globe in ISACHD activities

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Future Directions

- Promote **global** collaboration and operationalize stakeholder involvement in ISACHD activities
 - Education
 - Research
 - Health

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The international nature of ISACHD is valued, but we need to operationalize its mission by increasing awareness of ISACHD's values for the ACHD community around the globe. Active involvement of physicians, fellows in-training, and non-physicians in ISACHD activities and promotion of collaboration in the current ISACHD priorities (global education, global health and

global research) are paramount which align with the priorities set by the respondents. ISACHD will serve as a global platform (e-platform) of communication and collaboration for these priorities.

Members at the semi-annual meeting emphasized the need of engagement of the members in ISACHD activities. One important question is who to extend ISACHD's reach and relevance to ACHD providers and programs around the globe. Members favored a discussion forum for difficult cases / management questions (which could be one option to facilitate engagement of our members). This web-based forum would offer a special and unique value for our ISACHD members as it is accessible for members only. As a model, the International Society for Heart and Lung Transplantation (ISHLT) provides the ISHLT Open Forum which is very user friendly, safe and appropriately addresses privacy issues. The ISACHD Board is very interested in exploring this option.

Future Directions

- **Scientific and Business Meetings**
 - Move from North American to global presence
 - Expand joint scientific/educational sessions at national and international congresses
 - ISACHD “networking” meetings beyond North American events (Europe, South America, Asia,
 - Expanded role of regional representatives
-

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ISACHD’s activities have been and are too North American centred and do not meet its global mission as a global umbrella organization. The regional representative must take an active role to implement the mission of global presence which is important to peel the perception off ISACHD being a North American Society.

Activities include: endorsement of regional / national ACHD meetings around the globe, organization of joint educational sessions at regional, national and international meetings which has been implemented (e.g. ISACHD is the captain for the ACHD track at the WCPCCS 2017 in Barcelona, a joint ISACHD – ESC-GUCH session is organized at the ESC meeting 2017 in Barcelona). The members at the semi-annual meeting strongly encourage the board to have semi-annual meeting outside North America. The Board will consider different options, including to have one semi-annual meeting in North America and the second semi-annual meeting on another continent (e.g. Europe, Asia, South America on rotating schedule).

Future Directions

- **Research**
 - Stimulate, promote and facilitate collaborative research across the globe
 - Implement a process of ensuring high quality research with global aspect
 - Improve communication to ensure that ISACHD members are aware and have the opportunity to participate

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ISACHD does not have the infrastructure and financial power to conduct research as a society, but ISACHD will serve as a vehicle and facilitator for global, collaborative research as summarized in the above slide.

Future Directions

- **Newsletter**
 - Different style of communication:
 - 2 newsletters / year published after ISACHD meetings
 - Intermittent **news flash**
 - Summary of highlights of major conferences

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Global communication is the key for our success in the 3 domains: global education, research and health. We are overwhelmed with daily news and newsletters with a wealth of information are usually not read. An **intermittent Newsflash** with distribution of targeted, topic-based news is more effective. In the past, the newsletters were mailed BEFORE the meeting and did not include important information discussed at the meeting.

There will be a paradigm shift: **two newsletters** will be published **AFTER** the semi-annual meeting / annual business meeting or as needed. Summaries of highlights of ACHD conferences / ACC / AHA / ESC or other meetings in Australia, Asia, Japan, South America are thought to be of value. An intermitted Newsflash will be published as needed.

Future Directions

- **Journal Watch**
 - ISACHD responsible for ACHD section of the CHiP Network Journal Watch
 - Global panel of reviewers
 - Distribution of the ISACHD **Journal Watch** to members

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There was a duplication and overlap of the Journal Watch on ACHD: one was published by ISACHD, led by Dr. Gruschen Veldtman, the other one was published by the CHiP Network. In the future, there will be only one Journal Watch on ACHD published in the CHiP Network (www.chipnetwork.org); the CHiP Network journal watch covers the entire spectrum related to congenital heart disease. The ACHD section of this very comprehensive CHiP Network Journal Watch will be led by ISACHD, but it will be published in the CHiP Network in association with ISACHD and on the banner of ISACHD as of January 2017. Dr. Gruschen Veldtman continues leading the ACHD section and will supervise and mentor an international panel of reviewers for the ACHD section.

Future Directions

- **Position Statement**
 - Focus on topics with a clear global perspective and relevance
 - Peer review
 - Planned topics:
 - Challenges to overcome in establishing organized ACHD care
 - The advanced practice provider (CV team members) role in ACHD: essential skills and roles in optimizing team-based care

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ISACHD position statements must have a **global** perspective and relevance and cannot be a duplicate of any published guidelines by other authorities. A clear process will be implemented: the board decides and approves the topic of position statements and invites the members of the writing committee. Each position statement will undergo a peer review process. Planned topics are listed above.

Future Directions

- **Website**
 - Primary mode of communication
 - New design and focus
 - Public and “members only” sections
 - Dedicated sections for education, research, global health and CV team members
 - Estimated cost \$15,000!

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Future Directions

- **Website**
 - ACHD programs
 - ACHD training programs
 - Case discussion forum
 - Journal Watch
 - Expanded role of fellows
 -

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The Website remains the primary mode of communication, but it needs a new design and focus. The Website is also a vehicle to engage membership and our members in ISACHD activities (please see section ‘Priorities’). The ISACHD Board will further evaluate all options to improve the quality of the Website, but financial constraints may be a limitation.

Future Directions

- **Fees & Fundraising**
 - More money required for improvement of expanded ISACHD infrastructure (e.g. Website)
 - Anticipate a slight increase in fees
 - Explore fundraising and corporate sponsorship
 - All ideas considered
-

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As a group, ISACHD members indicated that they seek improvements in the ISACHD infrastructure (e.g. website, discussion forum) without a significant increase in membership fees.

Multiple strategies will be considered in order to accomplish this including the following

- (a) increase the number of paying members (by increasing global membership and engaging fellows early in their careers,
- (b) exploring industry funding/sponsorship, and
- (c) providing an option for donations at the time of membership renewal.

It is possible however, that a slight increase in fees might be considered.