

THE ACHD REVIEW

The following review is provided as a service for US ACHD professionals from The American College of Cardiology's Adult Congenital and Pediatric Cardiology Section's ACHD Working Group. *The ACHD Review* is a quarterly update of current ACHD activities provided by members of the ACC ACHD Working Group, invited ACHD experts, and edited by ACHD WG co- chairs Gary Webb, MD, FACC and Curt J Daniels, MD, FACC. *The ACHD Review* is an informal communication vehicle and as such the comments and views expressed may not be those of the ACC.

Last month we convened in Chicago for ACC.12, and for those who were able to attend, the meeting proved to be a rewarding experience for CHD/ACHD cardiologists and CCAs. The scientific sessions were well planned and well organized, and the presentations were outstanding. But, by far, the highlight of the meeting for many, including myself, was Jane Somerville, the 2012 Dan G. McNamara lecturer. There are generational differences as to our professional relationship with Dr Somerville. Most in the CHD profession have either heard of Jane Somerville, read her papers, seen her lecture, worked with her in some capacity or were trained by her. Especially in the ACHD world, the GUCH (Grown-Ups with Congenital Heart Disease) population, the acronym itself, is attributed most to Dr. Somerville. Therefore, with her place in CHD history and along with her well recognized candid, truthful, straightforward approach, knowing that she was going to present at ACC raised quite a bit of anticipation.

Her lecture was scheduled for 2:00, and at least 30 min prior, there was a sizable crowd gathering outside the doors of N228 McCormick Convention Center. It was as if we were waiting for a concert to begin with general admission seating. The doors flew open and everyone quickly lined up to enter the conference hall. At one point the door attendant got a little excited and called out to everyone to settle down, line up and enter slowly. It wasn't until about 10 min after 2:00 Jane Somerville took the stage. She didn't disappoint. Her historical account of CHD surgery and surgeons was quite entertaining and informative. She spoke of her upbringing and what brought her to medicine and eventually to congenital heart disease cardiology. She discussed surgeons as either "good ones or bad ones" and made no excuses that this was her lecture so she could say whatever she wanted.

She discussed her work in opening the first adolescent CHD ward in 1975 at the National Heart Hospital in London stating "the idea really came from the Toronto Hospital for Sick Children, They knew the sick kids who survived congenital heart disease grew up, but they were a kids hospital. GUCH was a way to use that idea. We didn't invent anything, we built on what went before."

The most interesting part of her lecture, for me, was the interview of Dr. Somerville by Carole Warnes. She was reflective about her life and her career and displayed an emotional side rarely seen by those who have followed her career. Jane Somerville, recognition of her remarkable career and this lecture were truly historic in the timeline of CHD.

This month's *ACHD Review* features a few initiatives from the past and a couple of new ones to keep you updated.

ACHD Subspecialty Certification

The ACHD Subspecialty Certification is an initiative in response to consensus within the congenital heart disease community, that the United States is facing an issue of how to best care for this new and rapidly growing adult congenital heart disease patient population. This petition is part of an effort to develop a comprehensive approach and provide the highest quality care for the one million adult patients with congenital heart disease. The 32nd Bethesda Conference, October 2000, and subsequently published in JACC 2001, introduced the concepts of the need for ACHD sub-specialty training and the roadmap to build a workforce. However it wasn't until January 2008, a pivotal meeting was held at the ACC Heart House with key stakeholders. It was then decided to move forward with a petition to create ACHD sub-specialty certification. ACC served as the lead administrative organization, with ACC, AAP, AHA, JCCHD, ACHA, CHF, and ISACHD appointing representatives to the petition writing groups. Once the ABIM and ABP petitions were completed, in June 2009, the ACC Executive Committee approved submission of the ABIM petition to the CV sub-board for initial review and comment.

In January 2010, The ABIM CV sub-board agreed to forward the petition to the ABIM Board of Directors. In November 2010 the ABP Board of Directors convened an agreed to let the ABIM take the administrative lead and the ABP and ABIM agreed to allow pediatric cardiologists to be eligible for sub-specialty certification. In September 2011, the ABIM submitted an application to the Committee on Certification, Sub-certification and Recertification (COCERT) for consideration. Initial review by COCERT of ACHD sub-specialty society took place early March. We will answer questions that were raised and expect a second reading by COCERT in the near future.

ACHD Training Directors

We recently held our biannual ACHD TD mtg at ACC12. There was solid attendance with good interaction at the mtg with a few new programs making their first appearance with interest in starting ACHD fellowship. We continue to encourage program directors to start the process NOW for developing an ACHD Training Program – it may take a couple of years to lay the groundwork and put the pieces in place for a successful fellowship program.

Throughout this process, we recognize that real and intense questions will arise and we plan to keep everyone in the CHD community informed and updated as the process moves forward. Through this forum (The ACHD Review), at AHA and ACC and through establishing a web-link via ACPC ACHD Working Group we plan to provide further information and announcements regarding ACHD fellowship, along with email and potential blog access to address questions, concerns and shared issues. On behalf of everyone involved in the certification process, here's to a busy and successful next couple of years!

Michael Landzberg, MD

Curt J Daniels, MD

ACC-ACHA PATCH Program

In an effort of remarkable partnership, geared at education of primary pediatric and internal medicine cardiologists regarding ACHD care principles, and improved networking of these foundation-forming cardiologists and supporting ACHD trained practitioners so as to improve access to life-long expert care for adults with CHD, ACC's Board of Governors together with the patient advocacy organization, the Adult Congenital Heart Association, have teamed to create a novel educational program that will be piloted this upcoming year. PATCH, or "Provider Action for Treating Congenital Hearts", focuses on the four critical areas suggested above, specifically:

- 1) Creation and dissemination of educational resources specific to the complex needs of the ACHD population and community
- 2) Enhanced awareness and implementation of ACC/AHA 2008 ACHD care guidelines
- 3) Improved access to ACHD-trained caregivers and centers of expertise in ACHD-care
- 4) Greater networking and collaboration between primary cardiologists and ACHD-trained practitioners.

Currently in its early phase of development, but with resounding support from the Governors and State Chapters of the ACC, PATCH plans to create (from existing and recognized ACHD clinician-teachers) a panel of available and supported local and regional PATCH educators/ambassadors for hands-on ACHD-specific knowledge dissemination, matched with provision, free-source marketing and utilization of resources including an on-line "ACHD Tool-Kit", pertinent print materials, and a website with links to banked educational resources, venues and webinars. PATCH programming is a combined effort of the ACC's Adult Congenital and Pediatric Cardiology Section (and the ACPC Education and Training Working Group), ACC Board of Governors (represented by Kentucky ACC Governor and pediatric cardiologist, Juan Villafane, MD, FACC), and the Adult Congenital Heart Association. While the partnering organizations will be reaching out to constituency for support in creating this pilot phase, volunteers are welcomed to participate in all aspects of PATCH.

For further information please contact leadership of the medical advisory board of [ACHA](#), the ACPC Education and Training Working Group of the ACPC of ACC, or your local State Chapter of the ACC.

Michael Landzberg, MD

ACHA Advocacy

Moving in the Right Direction - - -

Lobby Day 2012 a huge success – across the country! From the advocates who visited their members of Congress in Washington DC to those who sent emails from home – our message rang loud and clear!!

Nearly 80 advocates gathered in Washington DC on March 1st for this incredible opportunity to talk to their lawmakers about congenital heart defects. Hosted by The Adult Congenital Heart Association and Mended Little Hearts, the 6th Annual Congenital Heart Lobby Day brought together patients, family members, medical professionals, and supporters from across the country to connect with over 100 legislative offices.

The Texas Chapter of the ACC hosted a Welcome Reception for the advocates at ACC's Heart House on Feb. 29. Additional support was provided by the Louisiana, Georgia and Iowa Chapters of the American College of Cardiology.

This year's message rang loud and strong. We took time to celebrate the tremendous success we have seen from our past efforts, and used that energy to continue to motivate our members of congress to do more! The efforts in Washington were magnified by an additional 60 advocates who reported contacting their legislators via email.

Together, we asked our lawmakers to:

- Provide funding to the CDC to support **data collection** to better understand CHD prevalence and assess the public health impact of CHD.
- Support NHLBI's efforts to expand **research** targeted to the diverse life-long needs of individuals living with CHD.
- Join the newly formed Congenital Heart **Caucus**

Fruits of our Efforts- - -

New Congressional Congenital Heart Caucus: In February of 2012, Congressman Bilirakis introduced the Congressional Congenital Heart Caucus as a tool to communicate with Members of the House of Representatives about the important issue of congenital heart disease.

CDC Funding put to good use: In December of 2011, the 2012 budget was passed, including \$2M in funding to the CDC for CHD Surveillance. On Monday, the CDC announced plans to use that money!! The National Center on Birth Defects and Developmental Disabilities (NCBDDD) will fund pilot projects to develop and implement innovative approaches for conducting population-based surveillance of structural congenital heart defects. The work will focus on adolescents and adults and examining healthcare utilization and referral to timely and appropriate services.

The CDC has also announced plans to hold a meeting of experts to discuss research priorities in congenital heart disease. This meeting will include members of the CDC, NIH, researchers and medical professionals. ACHA has been invited to attend, as well.

Still work to be done - - -

We have seen huge successes in the past few months thanks to the advocacy efforts of people like you.

Continued CDC funding is not automatic. In this difficult economic climate we need to make ourselves heard to ensure the continuance of these excellent efforts.

Take action today, call or write your lawmakers. Ask them to keep the \$2M funding for the CDC for CHD surveillance. You can also encourage your Representatives to learn more about CHD by joining the Congressional Congenital Heart Caucus.

YOU can make a difference!

View the ACHA Lobby Day video at <http://www.youtube.com/watch?v=QMG-mX0U-4s>

Amy Basken

Amy Verstappen

AARCC

The Alliance for Adult Research in Congenital Cardiology (AARCC) was formed in 2006 as a research group to foster collaborative relationships between programs and investigators, to further and sustain research efforts, and to include the goals of innovative investigations, advancing knowledge, and improving outcomes. Since its creation, the group has published four multicenter studies involving adults with congenital heart disease. Additionally, they have partnered with the Adult Congenital Heart Association (ACHA) and received grant support from the National Heart, Lung and Blood Institute for two collaborative projects. Current projects are focused on 1) examining the extent of liver dysfunction in adults with Fontan physiology, 2) several investigations evaluating echocardiographic parameters in adults with repaired tetralogy of Fallot including aortic parameters and pulmonary regurgitation and 3) automated capture of electronic health data for adults with congenital heart disease.

The group is in the final stages of formally accepting bylaws that will allow for increased membership over time. However, membership is not the sole means of working with and through this organization: 1) non-member investigators and centers are encouraged to submit proposals to AARCC for multi-center research within the AARCC framework, sustaining primary investigator role with the applicant, and 2) applicants and non-member centers are encouraged to seek involvement with ongoing or proposed AARCC initiated projects appropriate for non-member centers. More information can be found on the group's website: www.aarcc.net.

Thanks to the ACC and the ACPC Section for providing meeting space at the AHA and ACC national meetings.

Anne Valente, MD

Joe Kay, MD

ACPC Clinical Practice Work Group

A National Voice for the

Complete Congenital Cardiac Team:

The January 13-14, 2012 ACC Cardiovascular Care Summit in Las Vegas provided the forum for an important congenital heart disease (CHD) breakout discussion for an eclectic gathering of congenital leaders; 49 CHD professionals (21 administrators, 27 cardiologists, 1 CHD surgeon). The summit addressed, in general, business and leadership issues important for alignment of hospitals and providers, cost effectiveness strategies, and reimbursement concerns. During the CHD breakout, this workgroup generated a preliminary survey, aimed to identify key CHD care issues from respondents across the nation, including the academic and private sectors.

The survey, developed and fielded under the auspices of the American College of Cardiology was sent to 915 CHD professionals, representing clinical providers and administrators. 145 surveys were returned for a response of 15.8%. 93% of the responders were ACC members, with 72% providing care within an academic center associated with pediatric and ACHD care, 6% at academic center with pediatric care only, 13.2% private practice with pediatric and ACHD care, and 4.9% with private practice with pediatric care only. 71% of the respondents were pediatric cardiologists and 13.2% ACHD cardiologists. 13 administrators, 7.1% of the respondents, also replied. The survey identified key strategic, operational opportunities for the profession of congenital heart disease care.

STRATEGIC

1. Define key clinical and business datasets
2. Establish dialogue with Children's Hospital Association (the new merged entity between CHCA and NACHRI) and other partners regarding aligning clinical and business operations.
3. Recommend new comprehensive metrics for US News and World Report survey, to represent the entire scope and scale of pediatric and adult congenital heart disease practices.
4. Identify best practice approaches to obesity in the pediatric CHD population.

OPERATIONAL

1. Develop best practices to educate congenital heart disease patients transitioning to adult congenital heart disease clinics.
2. Develop and implement best practices for comparative reporting (PHIS data).
3. Develop business and clinical dashboards for benchmarking CHD centers, exploring MedAxiom as a possible solution.
4. Develop a sustainable ACHD business model, ensuring sustainable clinical practices and provision for dollars to train the next generation of ACHD providers.
5. Develop a comprehensive CHD directory which will be widely and publicly accessible. This initiative is already underway through the ACC.

DATA

1. Identify opportunities to coordinate and align key data sources including, but not limited to STS, EPIC, IMPACT, ICD registry, ELSO, etc.
2. Expand upon current popular quality metrics which include mortality, complications, outcomes, length of stay, CLA-BSI, readmissions, infection, risk factors.
3. Define age continuum best practice quality metrics for common congenital heart disease lesions including, but not limited to, ASD, tetralogy of Fallot, TGA, Fontan, and possibly VSD and common outpatient chief complaints of chest pain and syncope.
4. Initial efforts underway to develop appropriate utilization criteria for outpatient echocardiographic imaging for patients with common chief complaints (syncope, chest pain, palpitations, and murmur).

The survey identified both the potential and the interest in collaboration across the age continuum for congenital heart disease patients, emphasizing the need to maintain close affiliation of pediatric and adult congenital heart disease providers and centers. The alignment of hospital administrators with clinical physician leaders will ensure the greatest opportunity for definition of most productive and efficient care, in the future. We should all be excited about the opportunity to partner through the ACC ACPC, with close collaboration among the Quality Metrics Workgroup, the Adult Congenital Heart Disease Workgroup, and the Clinical Practice Workgroup. Formalizing the ACC-ACPC section as the platform for advocacy, best practice and defining forum for value based congenital heart care will take an active engagement for us all. Goal: One organization to build synergy in care and best use of healthcare resources.

More detail about the ACPC Clinical Practice WG strategy will be in the May/June CHD focus issue of ACC's member magazine, *Cardiology*.

Robert Campbell, MD
Maryanne Kessel, RN, MBA

ACCCA

The Adult Congenital Cardiac Care Associate Research Network

Although still in its infancy, the Adult Congenital Cardiac Care Associate (ACCCA) Research Network is already impacting the delivery of care for patients with congenital heart disease. The network, which includes nursing, nurse practitioner, physician assistant and psychologist representation now includes 14 members with an expertise in adult congenital cardiac care and clinical research.

The ACCCA Research Network's latest accomplishment has brought attention to the fact that a large percentage of parents of children with moderate and complex congenital heart disease do not understand that their child will require life long congenital cardiac care. This project, which partnered with the Adult Congenital Heart Association and which was supported by the American College of Cardiology's Adult Congenital and Pediatric Cardiology Section and the section's ACHD Work Group was published in Pediatrics this past November. The results of this project, with enrollment of 500 parents from nine U.S. centers, continues the support of educational initiatives to improve the understanding of life long cardiac care for children with congenital heart disease. The network is also engaged in numerous other projects including a study to determine what teenagers and young adults, ages 16-25 years, understand about the type of care they will need in adulthood. This study has enrolled over 100 patients to date. In addition, the network is nearing completion on another study examining the contraceptive practices of women with congenital heart disease. More than 400 women have been enrolled to date from seven U.S. and Canadian centers.

The ACCCA Research Network is committed to improving the care of patients with congenital heart disease through collaborative multi-center research and looks forward to further growth and productivity in the years to come.

Sue Fernandes, PA-C

Disty Pearson, PA-C

22nd International Symposium on Adult Congenital Heart Disease in Toronto (May 30 to June 2, 2012)

After 2008, Toronto will be again the home city of this International Symposium from May 30 to June 2, 2012, which was held at Skamania Lodge, Stevenson, WA, in 2010, and in Cincinnati in 2011. This Symposium reflects a long partnership between the faculties of Oregon Health & Science University (Dr. David Sahn, Dr. Craig Broberg), Cincinnati Children's Hospital Medical Centre/University of Cincinnati (Dr. Gary Webb) and University of Toronto. It is a unique forum where medical professionals can meet their colleagues from around the world, and exchange ideas and information in the growing field of Adult Congenital Heart Disease (ACHD).

The meeting will be held at the **Toronto Marriott Downtown Eaton Centre Hotel** close to the famous Eaton Centre from **May 30 to June 2, 2012**. Information, on line registration and abstract submission will be available at www.uhn.ca/ACHDConference2012.asp. Paying CACH Network and ISACHD members will be offered a 10% reduction on the registration fee.

Beyond Saving Lives

In 2012, when more than 90% of children with congenital heart defects are reaching adulthood, the congenital heart disease community is beyond describing morphology and pathophysiology and saving lives. The ACHD community faces many challenges: '***Beyond Saving Lives***' is the theme of the Symposium and describes them best. The following hot topics amongst others will be discussed in plenary and breakout sessions:

- Supportive and end life care (advance care): an ignored challenge and urgent need for the growing ACHD population
- Bringing quality to ACHD Care (quality metrics in ACHD)
- I³ in ACHD – Imaging, Intervention and Innovation
- The Fontan disease: diagnostic and therapeutic challenges of a multisystem disorder
- Heart failure and heart transplantation: beyond drugs!
- The right ventricle: what I always wanted do to know!
- Pulmonary hypertension in ACHD
- Pregnancy and congenital heart disease
- Nursing in ACHD
- Global Health – session of the International Society of Adult Congenital Heart Disease (ISACHD)

Breakout sessions will feature case-based learning and are tailored to topics discussed in the Plenary Sessions. This will allow in depth discussion of unanswered questions with international experts in detail. ACHD nurses and advanced nurse practitioners will also have a major role at the Toronto meeting. **Dr. Ivan Rebeyka**, Edmonton, will be the distinguished speaker for the **Dr. William G. Williams Lecture** (Dr. G. Webb was the inaugural speaker in 2008). Poster presentations from all backgrounds (physicians, nurses) will provide the presenters a unique opportunity to present their scientific papers. The top three abstracts will be presented as oral presentations. Online abstract submission will open in mid February 2012.

I expect the Symposium to provide the best of science and education in this area of practice. The Program is designed for all healthcare professionals working with Adult Congenital Heart Disease and should familiarize participants with the latest clinical information on the diagnosis and management for ACHD. Please feel free to contact Carole Ryan (carole.ryan@uhn.ca) or Erwin Oechslin (erwin.oechslin@uhn.ca) if you have any questions.

Erwin Oechslin, MD

ACC's magazine, *Cardiology*, to print Congenital Heart Disease Focus issue

ACC's member magazine, *Cardiology*, will be devoting its May/June 2012 issue to Congenital Heart Disease. Domestic ACC members will receive a print copy of the Magazine via U.S. mail in late May.

The issue will provide further detail of many of the activities and milestones noted in the ACHD review. The CHD Focus issue of *Cardiology* Magazine may also be found [on line](#) after May 22.

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