President Update

Dear CACH Network Members:

This e-newsletter facilitates exchange of information among the 15 centers, allows us to present updates, and to highlight research, amongst other topics.

The Board is placing high priority on the following activities: 1) Area of Focused Competence (AFC) Diploma in ACHD; 2) CACH Network Research Investigators Committee.

RCPSC has established the AFC Diploma program for highly focused disciplines of specialty medicine that addresses a legitimate need, but does not meet the criteria for a subspecialty. AFC programs represent a highly specific and narrow scope of practice. The length of competency-based training typically consists of 1 to 2 years. The AFC Program is the home to acknowledge and to recognize competence in ACHD in Canada and is vital for our fellowship programs. A Committee including all stakeholders in the field of congenital heart disease will prepare the documents and apply for recognition of ACHD as a diploma discipline.

The Board has initiated a CACH Network Research Investigators Committee led by two Co-Chairs Dr. Ariane Marelli, Montreal, and Dr. Jasmine Grewal, Vancouver. Funding agencies are looking for evidence of synchronized productivity and for collaborative research. It is critical to tie the strengths of the CACH Network centers, to facilitate multicenter research projects and to mentor and to support young investigators.

Industry Canada has officially approved CACH Network to continue under the new Not-for-Profit Corporations Act. CACH Network AGM will be held in Vancouver: Sunday, October 26, 6 pm at CCC 2014.

Erwin Oechslin, President CACH Network

CCHA Update

The Canadian Congenital Heart Alliance (CCHA) is thrilled to announce the launch of our redesigned website, thanks to an “in-kind” donation from Pixel Sweatshop and a grant from CHEO (in return for posting information on Healthy Living in Kids with CHD). To mark the launch we have created a survey and are asking CHD patients, families, and healthcare professionals to participate so we can get some much-needed feedback (www.chaforlife.org).

In February the BC chapter of CCHA held the first Heart Warriors Walk in Abbotsford to celebrate CHD Awareness month, raising over $3,000. In May “Team CCHA” raised over $16,000 in the Cardiac Health Foundation of Canada’s Walk of Life, which will be split 50-50 between CCHA and cardiac rehab programs across Canada.

This spring, the CCHA again attended and presented at the Sick Kids Family Education Day, as well as their Transition evening – a great way to communicate the importance of life-long expert care. From September 11-14, the CCHA will be holding its 6th annual Beat Retreat camp for patients 18+. Details of the camp are posted on our website.

CCHA has two new brochures (adults and kids with CHD), as well as a new life insurance poster. You can view them online at www.chaforlife.org/posters-brochures. To order free copies for your clinic, email info@chaforlife.org (please specify your order)!

Patients contact me regularly to ask when we’re having another patient conference. If you’re interested in working with us to host a day/evening event (we will organize and fund it) please let me know. Options include a webinar involving several centers at once!

Shelagh Ross, CCHA president
info@chaforlife.org
www.chaforlife.org
Twitter: @chaforlife

If you have a comment, suggestion or update please send to jasmine.grewal@vch.ca.
What is CHiP Network?

Dear Fellow Canadians:

The CHIP Network, the Congenital Heart Professionals Network, has been designed to provide a single global list of all CHD-interested professionals in order to: Connect pediatric and adult CHD-interested professionals to events, conferences, research opportunities, and employment; Help participants keep up with the literature through a journal watch service; Bring the pediatric and adult congenital heart professional communities into closer contact; Offer a communication tool for critical issues.

The Network is all-inclusive and is comprised of everyone who considers themselves a congenital heart professional or administrator.

The Network helps partner organizations (congenital heart organizations which periodically need to communicate with their communities - of which there are now about 25, including the CACH Network) reach selected members of the congenital heart professionals community. This can be done locally, provincially, nationally, by professional types, and a host of other variables.

Please register now at www.chipnetwork.org. It only takes a minute, and you can unsubscribe at any time.

Please spread the word to other congenital heart professionals. Remember, this is not just an adult professionals facilitate. We're interested in all congenital heart professionals, and most of them will be working in pediatrics.

With best wishes,

Dr. Gary Webb, on behalf of the management committee.

Keep an eye out for Journal Watch!

This is an evolving CHiP Network initiative that provides subscribers with abstracts and commentary of up to date congenital heart articles of notable interest.

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RESEARCH SPOTLIGHT

The CORRELATE Study

CORRELATE (Canadian Outcomes REgistry Late After TEtralogy of Fallot Repair) is designed to evaluate the impact of pulmonary valve replacement on clinical status in adolescents and adults late after tetralogy of Fallot repair.

Inclusion criteria are repaired tetralogy of Fallot with moderate or severe residual pulmonary regurgitation, age ≥12 years, and ability to undergo cardiac magnetic resonance imaging evaluation. Target enrollment is 1000 participants across all sites within 3 years. The number of patients recruited as of May 15, 2014 across 7 sites is 120. Progress at the remaining 8 sites is as follows:

1. REB approval received and site contracts in place: St. Paul’s Hospital (Vancouver) and Jewish General Hospital (Montréal).
2. REB approval received with site contracts pending: Mazankowski Alberta Heart Institute and Stollery Children’s Hospital (Edmonton).
3. REB and site contracts in progress: BC Children’s Hospital (Vancouver), Alberta Children’s Hospital and Peter Lougheed Centre (Calgary) and Montreal Children’s Hospital (Montréal).

The core lab in Toronto is now established with a designated analyst, a dedicated location and state-of-the-art software. There are 74 completed cardiac MRI and we anticipate that MRI analysis will begin soon. Biobanking of blood and tissue at the time of PVR continues in Toronto with 18 patients recruited thus far. Discussions are underway to initiate biobanking in Halifax under the leadership of Dr. Camille Hancock Friesen. New study initiatives which have received REB approval include the application of the T1 mapping MRI sequences to the CORRELATE patient population (REB approval received at the Toronto General Hospital).

For information regarding the CORRELATE study, please contact the principal investigators, Dr. Rachel Wald (rachel.wald@uhn.ca), Dr. Michael Farkouh (michael.farkouh@uhn.ca), or project manager, Roula Raptis (raptiss@smh.ca).

The BAV Study

The BAV (Beta blocker and Angiotensin Receptor Blocker in Bicuspid Aortic Valve Aortopathy) pilot study is currently underway. Results of this study will help guide physicians on how to best treat patients with dilated aortas and BAVs and help prevent aortic dissection and premature death in this population.

This is a two arm parallel prospective, randomized, double-blind, placebo-controlled trial: BB vs. placebo and ARB vs. placebo. Patients who are eligible to take either study medication will be randomly allocated to participate in either the Beta Blocker (atenolol) vs. placebo arm, or the ARB (telmisartan) vs. placebo arm. Patients who are ineligible for either of the arms will be assigned to the other arm. The study will last 5 years with a goal of n=420. Inclusion criteria include any adults with BAV and a dilated aorta (>37 mm) with no contraindication to BB or ARB therapy and no contraindication to Magnetic Resonance Imaging (MRI). Primary endpoint will be the change in rate of aortic root dilatation as assessed by MRI. Secondary endpoint will include: 1) incidence of aortic dissection/rupture, 2) need for surgical aortic root replacement and 3) cardiovascular death.

A pilot study has already randomized 85 patients across 12 centers in Canada with pilot funding provided by CAnnCTIN (a CIHR sponsored cardiovascular research network). The clinical trial infrastructure is provided by Population Health Research Institute (PHRI), a joint research institute of McMaster University and Hamilton Health Sciences.

Fifty eight percent of the patients have been randomized to ARB arm: 42% to BB arm. Majority are male (78%), mean age of 47.2 ± 14.6 years, mean baseline ascending aortic dimension 42.8 mm. All patients have tolerated the run in phase of the study with no serious adverse event during the pilot study.

Dr. Judith Therrien
For further information regarding the BAV study, please contact the principal investigator (Judith.therrien@mcgill.ca).