

CCHA 2009 in review



Beat Retreat Camp's 1st year a big success

From September 25-27, 14 adult CHD patients gathered at beautiful Camp Quin-Mo-Lac north of Belleville, on the shores of Moira Lake, to share an unforgettable camp experience. More than a dozen adult CHD patients, accompanied by a cardiac care nurse practitioner, turned out for three fun-filled days. During their stay, "campers" partici-

pated in a wide range of traditional camp activities, including campfires, canoeing, archery, climbing wall, initiatives course, crafts, yoga, volleyball... and even a polar bear dip. Even better, activities were structured to give "campers" an opportunity to participate based on their physical ability and comfort level... with plenty of "down time" thrown in for socializing and relaxing. Based on the overwhelming success of our first Beat Retreat, plans are already afoot for the next one. If you're interested in finding your "inner kid" and participating in a little camp craziness,

send us an email at thebeatretreat@cchaforlife.org... we'll keep you posted on preparations for next year's camp.



Happy campers



Bold climbers!

Bill 178 passes second reading at Ontario legislature

On November 26, the Ontario legislature gave second reading to Bill 178 – a bill to declare February 14 as Congenital Heart Disease (CHD) Awareness day in Ontario.

Member of Provincial Parliament Dr. Helena Jaczek (Oak Ridges-

Markham), who put forward the private member's bill, spoke about congenital heart disease and the challenges facing patients and healthcare providers. She also discussed the need for greater awareness to improve the standard of care for adults, reduce wait times

for surgery, and better funding for clinics so they can provide the best care possible.

She was supported by MPPs Elizabeth Whitmer (Kitchener-Waterloo), Shafiq Qaadri (Etobicoke North), France Gélinas Nickel Belt),

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Bill 178



Christine Elliott (Whitby-Oshawa), Rick Johnson (Haliburton-Kawartha Lakes-Brock), and Garfield Dunlop (Simcoe North). They provided additional information about CHD and personal anecdotes.

The Bill received unanimous approval on second reading. In the spring, the Bill will be referred to the Standing Committee on Social Policy for review.

After the Committee is through with its review, the Bill is expected to return to the House for third reading, and hopefully, Royal Assent – hopefully by the end of the next summer.

It was a historic day for all CHD patients. CCHA wants to give heart-felt thanks Dr. Jaczek. We would also like to thank all those who turned out at the legislature to support Dr. Jaczek, including Dr. Oechslein and staff from the Toronto Congenital Cardiac Centre for Adults, and staff from Sick Kids Hospital.

2009 Cardiovascular Congress

CCHA connects with CHD professionals

The CCHA attended the Canadian Cardiovascular Congress for the second year running.

During the multi-day event – held this past October in Edmonton – the CCHA “worked” an attention-grabbing booth promoting awareness of CCHA and congenital heart disease (CHD). (Thank you to the Heart and Stroke Foundation of Ontario for picking up the tab for our booth space and exhibitor fees).

Patient volunteers – including CCHA President John Maceachern, CCHA board member Ted Thaler, and CCHA executive member Jennifer Graham – were on hand to answer questions and hand out CCHA brochures. More importantly, they forged new connections with CHD healthcare professionals from across the country and lay the groundwork for new regional chapters.

While in Edmonton, John and

Ted were also invited to attend the annual meeting of the Canadian Adult Congenital Heart Network (CACH Network) – an information-sharing network created for CHD professionals. At the meeting, John and Ted took the opportunity to update CACH Network members on a wide range of CCHA initiatives.

The CCHA is already making plans to attend next year’s Congress in Montreal.

More camp photos



"Polar Bear" Award recipients



It's harder than it looks!

1st annual International Congenital Heart Coalition



International Congenital Heart Coalition

The CCHA hosted the inaugural meeting of the International Congenital Heart Coalition (ICHC) October 7-9.

The meeting was the culmination of more than a year-and-a-half of hard work and planning by CCHA President John MacEachern and ACHA President Amy Verstappen, with encouragement from Dr. Erwin Oechslin, Dr. Michael Landsberg of Boston, and Dr. Barbara Mulder of The Netherlands.

Fourteen countries were represented at the meeting. John was the founding Chair of the ICHC, while Amy facilitated the meeting with incredible skill. The organization now boasts 21 member countries, all of which have patient-driven Congenital Heart



and Adult Congenital Heart Organizations.

At the conclusion of the meeting, John turned the Chair's gavel over to Ms. Lara Sydall of New Zealand, who runs the new Zealand Congenital Heart Organization and has her Masters degree in running not-for-profit charities. John feels that the ICHC is in great hands and will continue to grow, so he can now devote more of his efforts back to CCHA and our problems within Canada.

For more information please visit www.ICHCOnline.com.

CCHA partners with Sick Kids for educational event

CCHA was delighted to take part in Sick Kids' Family Education Day held on September 12 at the Marriott Hotel. More than 150 children with congenital heart disease and their families attended the event and listened to talks geared to the various age levels – from 5 year olds to parents. Ted Thaler and Shelagh Ross shared life experiences and fielded questions. Our booth was manned by Jennifer Graham and Toby Cox. Toby, Lori Constable-Smolcic, Ted, and Shelagh facilitated small discussion groups to gather parental concerns. All in all, it was a positive experience and we look forward to working with Sick Kids in the future.

Havin' a blast!: CCHA social gatherings

We're not going to let a little CHD get in the way of having a great time! At least that's the attitude of a growing number of CHD-ers, family members, and friends who have been turning out for CCHA social gatherings, meeting new people, making new friends... and having a blast.

During 2009, the CCHA hosted six social gatherings in the Toronto area. Most of the activities were designed for all ages... although we did slip in one pub night for the 19+ crowd. From limbering up at the lanes (bowling) to cramming it in the corner pocket (pool) to bolting

down bulgogi (eating Korean food), we've had some excellent outings. And we're already lining



CHD-ers and friends "strike" a pose for the camera.

up bigger better things for the New Year.

Bowling, pool, eating... what's next? We're looking at a number of options, including karaoke, laser tag, and indoor beach volleyball. Check out the CCHA website (www.cchaforlife.org) in the coming days to find out what's up next – and make a point of joining us.

If you'd like to be added to our "social gatherings" email list – or if you've got an idea for something you'd like to do – send us an email at tthaler@cchaforlife.com.

A plea for help!

CCHA is a volunteer-based registered charity and we need your help. We are looking for new funding to support the projects that will help people with CHD. All donors will receive a tax receipt.

We're also in need of people to help us fundraise – so if you have some time and expertise to share, please let us know by contacting communications@cchaforlife.org.

We would like to thank Heart & Stroke Ontario, Actelion, Medtronic, and the Bank of Montreal for their donations, as well as the many generous individuals who have donated over the past year. Your funds are being used responsibly to raise awareness about CHD and fund initiatives aimed at improving the quality of life and health outcomes for people with congenital heart defects.



Donating to CCHA is as easy as 1, 2, 3

1. Go to the CCHA website at www.cchaforlife.org.
2. Click on the “Donate now” button on the home page (clicking on the button will automatically redirect you to the CanadaHelps website).
3. Follow the steps on the CanadaHelps website.

Once your online gift has been processed, CanadaHelps will immediately email you a tax receipt.

You can also donate by sending us a cheque to:

CCHA
C4-233 Cross Avenue, P.O. Box 233
Oakville, ON L6J 2W9

Visit us at
www.cchaforlife.org

More about CCHA

The **Canadian Congenital Heart Alliance (CCHA)** is a 100% volunteer-based registered charitable organization made up of patients with a congenital heart defect, their friends, families, and the medical community. With your support, we aim to improve the quality of care for these patients, many of whom require life-long expert care.

Our Mission:

To improve the quality of life and health outcomes for individuals with congenital heart defects by: raising awareness, providing peer support and mentoring, and advancing research.

Our Objectives:

The objectives of the Canadian Congenital Heart Alliance (CCHA) include the following:

- Raising awareness of congenital heart defects (CHD) and the CCHA within the congenital population, medical community, government, and general public
- Providing peer support, mentoring and outreach programs to patients and families
- Advancing congenital heart disease-related research

