



CCHA "Heart-to-Heart"- Spring 2009

CCHA plans weekend "camp retreat"

Ever wondered what it be like to go to camp? Or, perhaps you've been to camp and would like to go again.

Now's your chance! The CCHA is organizing a weekend retreat – in a camp setting – for congenital heart patients 18 years of age or older. The retreat will be held September 25-27 at Camp Quin-mo-lac – a rustic, but comfortable camp 45 minutes north of Belleville.

Our goal is to give upwards of 50 "campers" a chance to: experience new activities in a medically supervised setting, connect with other congenital heart disease (CHD) patients, build "heartfelt" friendships, and have fun.

The camp will include a variety of traditional camp activities – all geared to the physical abilities and comfort levels of participants. There will also be plenty of down time for those who want to re-energize and socialize.

If you're interested in attending our first-ever camp retreat, send us an email at thebeatretreat@cchaforlife.org.

CCHA Needs You NOW!



To help us:

- represent you and 180,000 other Canadians with CHD
- promote awareness across Canada of CHD
- provide you with a platform to meet other CHD patients and exchange stories
- to improve the care CHD patients receive

We especially need expertise in the following areas:

- Accounting/bookkeeping
- Fundraising
- Camp volunteers
- Legal help
- Web design/management
- Press releases
- Government advocacy
- Mentoring

Whether you become an active member or not, we need you to help CCHA grow in order to advocate for Canadian with CHD. You will also be kept abreast of all of the latest developments AND be part of a growing and active community.....and it's free!

Sign up on our website www.cchaforlife.org and help us make a difference.

Donating to CCHA

If you'd like to make a donation to the CCHA, all you have to do is:

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. Simply follow the steps on the CanadaHelps website.

We rely 100% on donations, to help us cover the cost of a wide range of necessities, including information to hand out at conferences and meetings, the fees associated with attending local and international meetings to raise the profile of congenital heart disease in Canada, hosting a website, necessary legal fees, and numerous other costs associated with running a 100% volunteer-based national charitable organization.

Once your online gift has been processed, CanadaHelps will immediately email you a tax receipt. Donations received by the CCHA will be used to fund initiatives aimed at improving the quality of life and health outcomes for individual with congenital heart disease.

CHD announced at Ontario Legislature

On March 3, 2009, MPP Helena Jaczek presented an official statement on congenital heart disease in the Ontario legislature.

Dr. Jaczek's statement was the first step in a process to declare February 14 Congenital Heart Awareness Day. Several CCHA members and TGH Adult Congenital Clinic staff were on hand for this historic and important occasion.

Then on May 7, MPP Dr. Helena Jaczek introduced a private member's bill in the Ontario Legislature. It was a momentous day for all congenital heart disease (CHD) patients, as it marks the turning point in Ontario (with other provinces to follow) when CHD is recognized as a major health issue that deserves greater attention, particularly from policy makers.

You can find a transcript of Dr. Jaczek's statement at www.cchaforlife.org.

CCHA booth at Canadian Cardiovascular Society's 2008 Congress

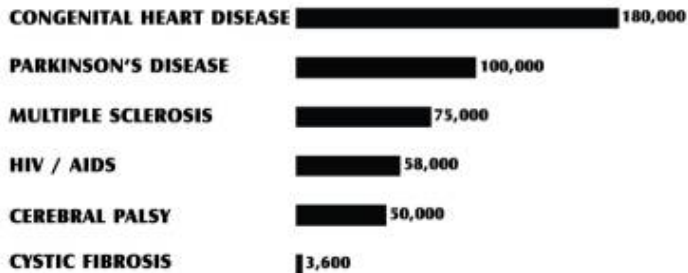
The CCHA made its presence known at the Canadian Cardiovascular Society's 2008 Congress, held last October at the Toronto Metro Convention Centre.

During the multi-day event – held last October at the Toronto Metro Convention Centre – the CCHA exhibited an eye-catching booth promoting awareness of CHD issues and the CCHA. Patient volunteers handed out more than 2,000 promotional pens bearing the CCHA logo, as well as a large quantity of CCHA brochures.

Thanks to graphics and visuals developed by one of our talented volunteers (including the one below), the CCHA booth attracted considerable interest and a number of compliments. The CCHA is already making plans for this year's Congress in Edmonton.



CANADIAN POPULATION DISEASE STATISTICS



CCHA spearheads effort to ramp up CHD research

The CCHA and Heart and Stroke Foundation of Ontario (HSFO) brought together leaders from healthcare, government, funding, and patient organizations for a half-day workshop aimed at advancing CHD research.

The overriding goals of the workshop – held in March at Toronto General Hospital – were to: build consensus on priority areas for research; identify opportunities for leveraging existing capacity in the research community; and encourage funding organizations to consider future investment in CHD research.

The CCHA and HSFO are currently drafting a report based on input gathered during the workshop. The report will be used as starting point for a working group focused on developing a coordinated research strategy for CHD.

CCHA president named Chair of the International Congenital Heart Coalition

In March 2008, CCHA President John MacEachern was invited to Chicago by the International Society of Adult Congenital Heart Defects, along with the Americans, Swiss and Japanese patient representatives, to create an international adult congenital heart coalition – the International Congenital Heart Coalition (IHC).

To date, IHC participants include Australia, New Zealand, Japan, Russia, U.S., Canada, The Netherlands, Scotland, England, Belgium, Denmark, Finland, Germany, Greece, and Switzerland. The goal is to create awareness and improve care and research of CHD worldwide, regardless of political ideals and borders.



It is anticipated that the first meeting of the IHC will take place in October of this year, in Amsterdam. So far, 18 countries have expressed interest in attending.

MacEachern, who has been named Chair of the new organization, says the IHC has an important and challenging task ahead of it. But he notes that "the support and enthusiasm of the international CHD community has been overwhelming."

"With the backing of world renowned specialists, such as Toronto's Dr. Erwin Oeschlin, Dr. Mike Landzberg of Boston, and Dr. Barbara Mulder of the Netherlands, I have no doubt that IHC will succeed," he says.

CCHA launches monthly social gatherings

The CCHA is now hosting monthly “social” gatherings in Toronto for CHD patients and their families. The informal gatherings will give patients a forum to come together and “connect” with others.

The next social gathering will be held June 5, from 7 – 9:30 p.m., at The Loblaws Cooking School, Empress Walk, 5095 Yonge Street, North York, Ontario.

For more information, please contact us at communications@cchaforlife.org.