



HiRO Newsletter

For Patients by Patients



Welcome to our inaugural newsletter for arrhythmia patients written by arrhythmia patients. We are very excited to offer this publication as there is so much we as patients want and need to know. Our hope is that we are able to fill this newsletter with valuable information and we encourage you to let us know if there is anything important you would like to see. If you would like to be a contributor, share your story, offer ideas for future newsletters or simply give us some feedback, please contact us at hironewsletter@gmail.com



Good News Everyone!

By **Vickie Pynn**

On March 9, 2016, The Children's Hospital of Eastern Ontario (CHEO) announced it had reached deal that ensures Canadian public sector hospitals and laboratories the right to test for Long QT syndrome for Canadian patients.

It hasn't always been this way. Until now, Transgenomic has held the patent on testing for LQTS and blood samples had to be sent to private labs in the US at considerable cost. Under this new agreement, these life saving tests can be sent to labs in Canada at 50% of the previous cost, patients will get results faster and be able to start their treatments sooner.

Not only will this agreement help people with LQTS, but this agreement will act as a model for public access to future gene patents. The total number of human genes is estimated to be between 20,000 and 25,000. Some of these genes are patented by private companies, the government and individuals. You can read more about this lifesaving agreement at <http://www.cheo.on.ca/en/gene-patents>



Be a Patient Voice

By **Vickie Pynn**

As a patient, family of a patient or a caregiver, have you ever thought that you had ideas that could make things better in our healthcare system but had no idea how to make yourself heard? I know I have. I recently found out about two ways I could volunteer in this capacity and to help make a difference in the big scheme of things. More and more, hospitals and clinics are asking for their patients to have a voice in their programs and delivery of services and I couldn't be happier. It only makes sense right? To collaborate with the people who can help them be the best that they can be in a world where our healthcare dollars are stretched to the max.

One way is to become a part of the Patient Voices Network (PVN) which started in 2010 and currently boasts 1850 patient volunteers. PVN matches patients, families and caregiver volunteers to healthcare providers within many different health regions who want to hear about the patient experience. It's easy to sign up online at <https://bcpsqc.ca/about-the-council/patient-voices-network/>. Once you fill out the online application form, you will be contacted by an Engagement Leader, there will be a short interview by phone and you will be asked to attend an orientation. You can be involved as much or as little as you like, be it simply filling out surveys, participating in focus groups or participating in long term placements. There are so many interesting ways for you to contribute. As they are finalized, the opportunities are sent out via email, when you find something you are interested in, you are required to fill out a short survey to apply for the placement, and you are notified if you have been accepted.

Secondly, if you are a member of the public who lives or works within Vancouver Coastal Health's regional boundaries you can volunteer by joining the Community Engagement Advisory Network (CEAN), there are currently approximately 160 active volunteers. You can join by downloading an application at <http://www.vch.ca/get-involved/community-engagement/have-your-say/join-us>. Like PVN, once your application has been submitted, you will be contacted by phone for a short interview and be required to attend an orientation before taking on any placements. A weekly newsletter is sent out naming all of the volunteer opportunities they are recruiting for and you sign up for the ones that interest you, they let you know when you have been accepted.

My experience with both PVN and CEAN has been outstanding, it is a very rewarding way to volunteer. It's been a very cool experience and I have met many wonderful, caring people. When you become engaged on a committee, you are part of the team, you are warmly welcomed and your contribution is definitely appreciated. I have learned so much and I continue to be surprised that my experience within the healthcare system can be of so much value. If you are looking for a way to give back and you have some spare time, I would definitely suggest that you give volunteering as a Patient Partner a try.



Research Projects

By Heather Joe

Inherited heart rhythm conditions are complex and cardiologists have many questions about how best to diagnose and treat these conditions and the families affected by them.

We are currently enrolling patients into one of three national registries and our local registry:

- ❖ Cardiac Arrest Survivors with Preserved Ejection Fraction Registry (CASPER)
- ❖ Canadian National ARVC Registry
- ❖ National Long QT Syndrome Registry
- ❖ The University of British Columbia/Vancouver Inherited Arrhythmia Research Data Registry.

These registries collect the healthcare information of participants with the goal that it will lead doctors to a better understanding of inherited heart rhythm conditions which may lead to improved care for individuals with these conditions.

Other projects currently enrolling patients:

Long Term Monitoring to Detect Risk of Sudden Death in Inherited Arrhythmia Patients

- ❖ This registry is for patients who have decided to have a specific long term cardiac monitoring device to monitor their heart's rhythm.

Novel Investigative Tools in Patients with Suspected Inherited Heart Rhythm Disorders

- ❖ This study uses two new devices to compare their validity with the standard cardiac tests for patients being investigated for an IHRC.
- ❖ A new continuous ambulatory ECG monitor that is designed to provide up to 7 days of continuous recording. It can even be used in the shower!
- ❖ A handheld ECG device that measures a single lead ECG.

Exercise and Severity of ARVC

- ❖ This study collects information about the types and frequency of exercise done by patients with ARVC and to compare this with their medical information



An Act to Prevent Genetic Discrimination in Canada

By **Heather Joe** on March 11

Canada is the only G7 country that does not protect genetic test results. Senator James Cowan is trying to change that. He has introduced Bill S-201, the Genetic Non-Discrimination Act, which would protect your genetic test results. This Act would prevent insurance companies and employers from requiring you to produce results from your genetic tests. As of writing this piece, the bill has passed two readings and is currently in a Senate committee. If it passes a third reading the bill will go to the House of Commons for approval before coming into law.



Just for Fun - Monthly Challenge

This month's challenge will be - Send us anything to do with the word "heart", a photo of something you love, your favourite quote, a piece of art, a poem and tell us why you chose it. We may feature it in our next newsletter. Please send to hironewsletter@gmail.com



Patient Resources

Cardiac Arrhythmia Network of Canada (CANet): www.canet-nce.ca

Canadian Genetic Heart Rhythm Network (CGHR): www.heartrhythmresearch.ca/i.php

SADS Foundation: www.sads.org

BC Inherited Arrhythmia Program: <https://sites.google.com/site/bciaprogram/home>



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