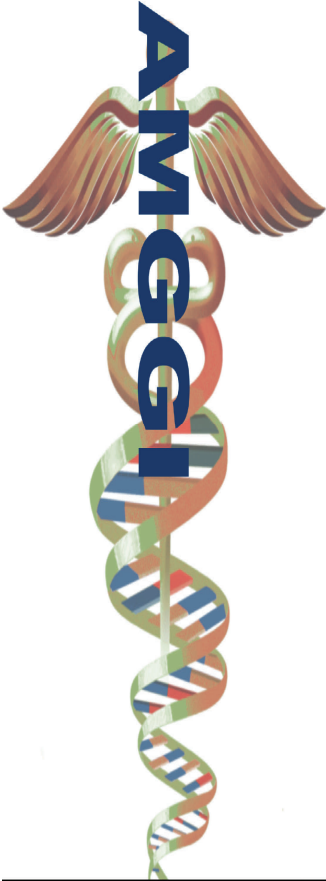


# NEWFOUNDLAND AND LABRADOR HEREDITARY DEAFNESS NEWSLETTER

WINTER 2009

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## Hello from the Recruitment Team



As I write this, we are in the midst of a “snow squall”, as defined by the weather office - in other words I can’t see across the road to the CBC building. Then three minutes later, the sun comes out and warms my work space to sauna levels of heat. Such is life in this province in winter.

I hope everyone had a wonderful break over the Christmas season and had time to relax with friends and family. We weren't able to get a newsletter out in time to wish everyone happy holidays, so these are belated wishes for the season.

Things are humming in our little office, recruitment is ongoing and business is booming in Terry’s lab upstairs. We have 107 families in our database right now - people who have signed consents - plus another 31 families who have expressed an interest in our study but have not yet sent back their forms. We try to contact people monthly but as there’s only one person doing this job, it’s often not that frequent. Count this as a reminder to dig out your brown envelope and either complete the forms or give me a call or e-mail so I can help, and answer your questions.

May 21st to 24th is the 2009 CHHA Conference and AGM—it is being held here in St. John’s this year and our study will have an information booth there. Kathy and I hope to man the booth, or I guess we should say “woman” it, and look forward to meeting some of you, as well as catching up with people we met in Grand Falls-Windsor last year.

As you know, CHHA-NL have been so supportive of us and our research. We are on their web page and they regularly post our newsletters. Of course Myrtle’s face is on our second page. Turn over and read her excellent article.

As Myrtle says, years ago there was nothing to offer people with hearing loss other than hearing aids. Now, not only are there many helpful technical aids but you also have the support of the association.

### Contact Information



Please feel free to contact us with your questions, comments and suggestions.

If you have moved or are moving or wish to receive mail at an alternate address, please write or call us.

We would appreciate comments or suggestions for future newsletters.

As always, we’d like to thank everyone for their help, input, participation and contact. We love to hear from you, and we constantly say, research would not happen without people like you.

*Carol*

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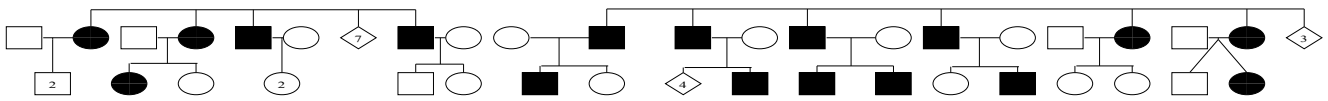
Funding for our project by:



CIHR IRSC



Office of the Human Investigation Committee (HIC) 709-777-6974  
Email: [hic@mun.ca](mailto:hic@mun.ca)



## The Emotional Side of Hearing Loss—by Myrtle Barrett

I grew up hard of hearing; looking back at my life, I had a lot of unanswered questions. Now I am late deafened and I still have the same questions but I seem to have more answers. The question that bugs me the most is WHY ME?

When I was a child I felt that I had done something bad that caused me to not be able to hear. I hid it until, at aged 16, there was no way I could hide anymore. If I wanted to pursue my dreams of graduating from school and going on to something which I felt would be rewarding and exciting, then I had to stop living the lie. All was *not* well and I could *not* hear.

I had arrived at the point where I saw that hearing loss was holding me back. The only answer at the time was a hearing aid. Actually, 40 years ago, the only answer to hearing loss was a hearing aid!!!

Technology has been very kind to the hard of hearing over the years, and while there are still gaps, we are lucky to have state-of-the-art hearing aids, cochlear implants, captioning and all those technical aids that serve us well in our schools, workplaces, families and communities.

Yet, there is something that technology will never help with and that is the emotional side of hearing loss.

I jokingly say that when I graduated from being hard of hearing to late deafened, I felt that I did a great job of accepting the loss and moving on. Yes, it was very difficult, but I am a strong person and I knew what I had to do.

Not everyone is that lucky. In my volunteer work with CHHA-NL I have met many people who have allowed their hearing loss to basically “own” them. No matter how powerful the technology and how effective it is for many hard of hearing people, there is always an emotional side of hearing loss.

People with hearing loss live in a world that not everyone can understand. They live in a world where there are many expectations of them based on the fact that few really understand the issues that come with the various types and degrees of hearing loss. I no longer wear a hearing aid but I still remember the anger when someone told me to “turn up the hearing aid” or that “I heard what I wanted to hear”. I did not help matters by being reluctant to talk about it. I tried to cope as if nothing was wrong, and that put me in the line of fire for all those stressors, i.e. fatigue, embarrassment, and the list goes on!

Living with hearing loss and hiding it, took up so much extra energy. It was bad enough just coping with the struggle to hear but I had to be good at keeping the secret, finding inventive ways to listen and live in fear of being found out. So much wasted energy when all I had to do was say “hey I have a hearing loss, here is what we can do to help each other communicate”!

Many years later I have a different outlook on hearing loss. Some of it comes from the fact that as a person with hearing loss I felt it was my job to understand that loss and to educate my family and friends on what it actually meant in terms of communication.

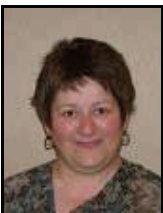
The other side comes from the fact that as an advocate and a volunteer I have met many people who struggle and continue to be reluctant to talk about it. I saw lives destroyed by the inability to cope with hearing loss. I saw relationships failing, I saw people depressed, I saw young married couples afraid to have children in fear that the gene would be passed on. I saw youth with low self esteem. I saw seniors isolated in their homes. I saw so much of how the emotional side of hearing loss controlled the person.

I encourage people to be more assertive and ask for what they need to help them hear better. Most of all, I encourage them to let go of the shame.

So, yes I have come a long way in terms of how I live with my hearing loss and I am always excited to find out about new technology and new research. I am at a point now where I know and understand hearing loss more than ever and it has made me more accepting and more comfortable of who I am as a person. I have reached the point where I know that my hearing loss does not define me but is part of me.

I was really excited when Dr. Terry-Lynn Young and her team started the Genetic Hearing Loss project in NL. Why? I guess because no matter how strong I have become, no matter how accepting I am of my hearing loss, I still have that little bug inside me that every now and then asks WHY ME? I know from all the people that I have met and will continue to meet that is it very important to them to understand WHY. Maybe, just maybe, this research project will be able to answer the question,

WHY ME?



Myrtle has had a progressive hearing loss since birth and has been late deafened for many years. She is a Social Worker by profession and an avid advocate for people with hearing loss. She is currently the President of CHHA-NL and a Director on the National Board of the Association