# BC HANDS & VOICES

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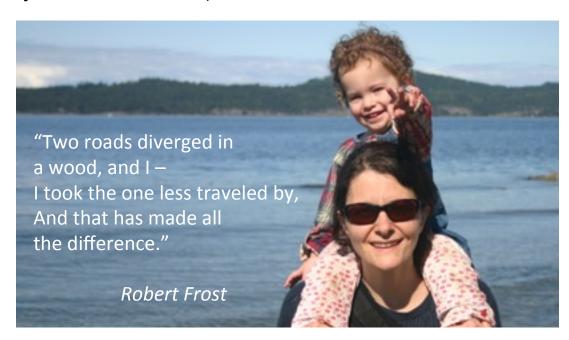
We are a parent/ professional collaborative group that is unbiased towards communication modes and methods, believing that families will make the best choices for their child if they have access to good information and support.

Our goal is to support families in achieving successful outcomes for their children.



### A Road Less Travelled

by Jen Gow & Dom Brecher, Vancouver BC



While downtown Vancouver rioted after the Canucks lost the Stanley Cup final in 2011, our own world came tumbling down around us: we had just received news beyond doubt that our six week old baby, Connie, was deaf.

Just two weeks after her birth, Connie failed the newborn hearing screening test. Having not given a second thought to the appointment, we were shell-shocked. A lot of babies fail the screening test only to have their normal hearing confirmed through

the full-blown diagnostic tests. Nevertheless, we were terrified at the prospect of Connie not being able to hear properly.

We had to wait four excruciating weeks until Connie could have the diagnostic tests. Even when the day arrived, the wait was not over. Testing a baby's hearing is no easy feat; they need to be in a deep sleep so that the electrical equipment can accurately read the brain's response to the sound stimuli. After three painfully long appointments, we

were finally told that Connie had a profound hearing loss in both ears.

Neither side of our family had any prior experience of hearing loss, and neither of us knew anybody with a hearing loss. Why are we not aware of deaf people in our community? Are they so poorly integrated that we don't cross

paths? What does it mean to be deaf? We had no clue. Our saving grace that day was the response the audiologist gave to this very last question; she told us that she herself had a severe hearing loss. We were gob-smacked. We had been talking with her all day and never would have realized that she had any trouble hearing! That was the beginning of our steep learning curve, studying the A to Z of hearing loss in our modern world.

Because Connie's hearing loss was profound,

we were told that she might be able to get a cochlear implant. A what? We were astounded to learn about these "bionic ears" that help deaf individuals to hear and be part of the hearing world that we take for granted. We were told that there are deaf and hard of hearing kids in BC who can not only understand speech and other everyday sounds around them but who flourish in the hearing world, playing musical instruments and learning second languages.

But the journey to this point would be a slow and sometimes upsetting one while Connie's suitability was assessed over her first year. First came the hearing aids, and you need to have eyes on the back of your head and three extra pairs of hands to keep hearing aids on a three month old. And then came the seemingly endless appointments: the hearing aid audiologist, cochlear implant audiologist, surgeon, teacher of the deaf, sign instructor. These are some of the exceptional people who worked tirelessly (and continue to do so) to give Connie the best start possible.



Despite learning all sorts of ways to focus Connie's attention on the sounds around her, it slowly became apparent that even with hearing aids, she wasn't able to hear a whole lot: a 90 decibel shaker held close to her ear – yes; speech – no. This was eventually confirmed by a series of behavioural tests as she got closer to her first birthday. At the same time, she was old enough to have the CT and MRI scans necessary to assess her suitability for a cochlear implant. They would

tell us if the internal anatomy of her ears and hearing nerves could "accept" implants. Although rare, there are instances where a cochlear implant just won't work. This was the moment that we had been holding our breath for all year; would Connie be able to enter the hearing world, or would her hearing remain very restricted?

We're delighted to say that Connie received what to us was the best birthday present possible. Just two days after her first birthday, Connie got two cochlear implants. She's a ground breaker, being only the second child to receive two implants at once in this province. Unfortunately, the magic fairy was unable to deliver the implants during the night, and so

Connie had to undergo a 7½ hour surgery - the longest day of our lives.

We're through that now though; Connie recently turned two. Cochlear implants are no overnight cure, as some YouTube clips could make you believe. The amount of sound she had access to gradually increased over many months, while Connie received intensive habilitation therapy to teach her how to listen, how to interpret the sounds she hears, and how to talk.

There were times during Connie's first year when her lack of response to sound despite our sustained efforts with the hearing aids was discouraging, even painful. However, the bag of tricks we learnt has stood us in good stead, and helped Connie get off to a flying start with her cochlear implants; she was quick to accept wearing them, as well as to absorb the listening world and join in with her own voice. Within a year, Connie went from barely vocalizing to stringing together four word sentences.

As I'm sure you can tell, we are thrilled that Connie has this opportunity to hear. But we also stand tall in saying that our daughter is beautiful, and part of this beauty is her deafness. We chose a route of total communication for Connie and our family. As Connie reached the developmental stage where language emerges, the doors to sign and oral language opened simultaneously; around the time of Connie's cochlear implant surgery, she started to reciprocate our ASL efforts. As hopelessly unilingual parents, we are proud of Connie's bilingualism. It helps her when she's not wearing her implants, and compliments her spoken words. As she grows, we hope it will help her identify with deaf and hard-ofhearing peers, and boost her self esteem.

This path less travelled has been, and will doubtlessly continue to be, a bumpy one. It has also been wildly enriching. Above all, perhaps, is the clarity that it lends to our values and priorities in how we choose to live our lives; we sweat the small stuff less and realize how very lucky we are.

#### PARENT COFFEE NIGHTS

#### We hope you can join us to:

- Get to know other parents of kids with hearing loss
- Share ideas that support your deaf or hard of hearing child... or just come to listen
- Have a night off with warm drinks, yummy treats and good conversation

WHEN: 7:30 - 9:00 pm

WHERE: #27-7488 Southwynde Ave., Burnaby (Look for the blue & orange balloons)

Mark your calendar with these dates and we'll save you a spot on the couch!

CONTACT: Anja Rosenke at arosenke@telus.net to RSVP or with any questions.

\*Please note in March we will meet on a Thursday evening in combination with the BC Hands & Voices AGM. Stay tuned for details about a guest speaker. Time and location TBA.





# **Collaboration • Cohesion • Community**

By Gina Cooper-Watt, Campbell River, BC & Anja Rosenke, Richmond, BC

BC Hands & Voices (BC H&V), Guide By Your Side Program (GBYS), Family Network for Deaf Children (FNDC), Canadian Hard of Hearing Association BC Parents' Branch, (CHHA – BC Parents' Branch), and Provincial Deaf & Hard of Hearing Services (PDHHS) jointly hosted a family picnic on June 8, 2013. The mission of all these organizations was inclusion and the goal was a social event that would bring together the peoples of the very diverse deaf/hoh population here in BC.

Our collaborative efforts were successful and resulted in a whopping 250 people coming out to enjoy the festivities on June 8th. Families and individuals enjoyed themselves at the beautiful grounds of Provincial Deaf/Hard of

Hearing Services (PDHHS) in Burnaby, BC. We all mingled, networked, played, shared stories, ate, and most importantly felt welcome using our various communication styles.

PDHHS' Victory Hill site provided a superbly spacious outdoor environment with a grassy area for sitting and relaxing, and a paved area which was perfect for playing basketball and road hockey. There were also information booths set up by the three parent organizations (BCH&V, CHHA, FNDC) as well as an arts & crafts nook. The kids eagerly lined up for face-painting, airbrushed tattoos, and balloon animals, which were provided by artists from A-Star Art Parlour. A huge bouncy castle was kindly shared by the Peterson family, and pro-



vided hours of tumbling and fun for the younger crew.

Throughout the day, families were able to learn more about the many programs and services offered throughout BC for families of deaf/hard of hearing children in BC.

Family Network for Deaf Children advertised their popular Hornby Island Family Deaf Camp, which is held every summer, as well as other wonderful events and services for children when they progress into Kindergarten and become involved with the Deaf community.

Deaf Youth Today (DYT) staff made the rounds talking about all the fun to be had for school-aged children during their summer program weeks.

Family and Community Services (FCS) also mingled with families and communicated all the learning and fun to be had for families with school-aged children.

CHHA - BC Parents' Branch was represented by several board members who were there to offer support to families with hard of hearing school-aged kids. As well, the deaf/hoh young adult volunteers, who are active in the CHHA Young Adults Network (YAN), were much appreciated that day.

Board members and volunteers from BC Hands & Voices were on hand, mingling

and introducing families to each other, and sharing information about their roster of events and member benefits.

> PDHHS' Family and **Community Services** made it possible for an event of this scope to take place by sharing their venue, providing staff and welcoming everyone to Victory Hill.

We all enjoyed a great barbecue lunch and the tremendous spread of homemade desserts. A big shout out to Roger and the DYT staff who manned the barbecues and ensured that

everyone was well fed! And thank you to the many people who contributed

> to our potluck by baking or bringing desserts to share.

> > If success is measured in smiles, new friendships, full tummies, happily worn-out kids and a vibe of unity...well then, we certainly outdid ourselves. We look forward to seeing you all again at our next joint event. Stay tuned!

For more information about these organizations, to sign up to receive emails and newsletters, or just to find out how

you can get involved, please check the fol-

lowing websites.

www.bchandsandvoices.com www.fndc.ca www.chhaparents.yolasite.com www.mcf.gov.bc.ca/pdhhs

## Inject a little Music into Communication Therapy!

By Gina Cooper-Watt, Campbell River, BC

I admit it, I am a research junkie. When my daughter was born, I became a "Google Mother." As I sat at the computer, rocking Sara in one arm and perusing the internet with my other hand on the mouse, I would read fascinating articles on parenting, and experiment with many of them.

One particular parenting site claimed that exposing your baby to classical music could stimulate her brain and make her smarter. ("The Mozart Effect"- a theory which has now been debunked.) My daughter spent many hours each day playing and listening to Mozart and other classical musical legends, all the while not hearing anything, and possibly wondering why mommy was dancing around the house with a proud flair at the thought of her

found myself Googling. This time, I was researching music and deafness.

I came upon a very interesting article describing how Music Therapy can play a role in the speech development process for the children with hearing loss, published by our city's Music Therapy Association.

Of course, I enrolled my daughter in private music therapy lessons at the association, group music therapy classes at our Outreach Organization, a playgroup where singing played a part in the structure of the class, and a toddler dance class. I also found an online support group with a member who happened to have a lot of knowledge with regard to cochlear implants and music. He suggested flooding your

child's ears with songs that had long, deep base lines such as Barry White and Isaac Hayes as this style of music has less disturbing factors and interference than other songs. I became an official "Pageant Mother" to my somewhat concerned yet curious family members. Could all of this really help Sara learn to speak more effectively?

Music therapy can lend itself to traditional auditory training by providing an alternative and pleasurable environment

in which to help a child learn to listen. Both speech and music contain pitch, tone, rhythm, timbres, durations and intensities. Children can learn how to distinguish, identify and understand these sounds with careful exposure to



brainchild becoming a famous gifted "something or other!!" Oh, the irony.

This experience etched itself in my mind, however, and shortly after my daughter was identified with profound hearing loss, I once again them. Music therapy can become a motivating tool and can enliven speech therapy sessions!

Furthermore, music therapy can also be effective in teaching children who use equipment for listening how to pay attention to sounds, the differences in sound, recognizing objects and events from their sounds, and how to use hearing to determine the distance and location of sound.

My daughter's curiosity level definitely peaked while exposed to all the different musical instruments, during her private and group music classes. She would stare at, and try to mimic the music therapist's mouth movements as she sang at various levels. The group music class certainly provided a fun family environment where all we parents would gather around the music teacher, dance with and sing to our children, take turns playing an instrument, sing a line of a song and listen to the sounds of everyone's differing voices.

Music facilitates family bonding! "Dancing with the Stars" would play every Thursday evening while daughter and mommy would take turns as Daddy's dancing partner. We would do our best to sing along to every song, keep the beat and find the rhythm to every dance style. We learned as well, through many humorous evenings, that my partner is a wonderful baritone and I am a natural at the Rumba. We now tend to leave the singing to daddy and the dancing to mommy to best offer our natural 'gifts' to our child.

Music can be a wonderful way to help children learn routine transitions and help prepare them for a sound sleep as well. Singing bedtime stories to your child can help your child to not only recognize and attach meaning your voice but also teach self-soothing techniques and emotional connection through tone of voice. Music can induce physical relaxation and help set an emotional tone of peace and well-being needed for a good night's sleep.

Rhyming is also essential to speech, language and literacy development. Songs such as The Wheels on the Bus, Hey Diddle Diddle and the Itsy Bitsy Spider all incorporate rhyming and repetition that help develop an awareness of speech sounds. By singing songs loaded with early developing sounds such as p, b, t, d, k, g, and m, you can possibly give your child a 'head start' to great listening and speaking skills.

At two years of age, my daughter's attention span would only last half an hour but it certainly gave us enough time to expose her to a wide range of sounds, help to stimulate the auditory nerves, and hopefully set a foundation for learning to listen.

I also discovered through research that deaf people not only enjoy but benefit from music. Evelyn Glennie, a famous deaf percussionist, and subject of the fascinating film "Touch the Sound, explains how she "feels" music through its touch and vibration.

While I don't claim that music therapy is a critical component in the speech development process, in my opinion and personal experience it definitely was a stimulating experience.

You don't have to become a "Pageant Parent" either. That phase was short-lived with me as I do not want to burn out in this journey. Learning is an ongoing process and now we, as parents and partners, involve our daughter in just one 'extra-curricular' activity per season to enhance speech therapy.

What I really liked about our experience with Music Therapy is that it made therapy fun. As a cochlear implanted child, with years of communication therapy ahead of her, I am really striving to ensure my daughter's childhood is filled with happy, fun memories, not a lot of tedious therapy sessions and 'forced' communication training. To me, this cochlear implant journey and all of its therapy and training is about being as natural and as fun as possible.

#### **Thank You**

Thank you to the following organizations for their generous support:

Gwyn Morgan and Patricia Trottier Foundation
BC Early Hearing Program
BC Children's Hospital Foundation

Your donations will go towards providing more support to families with deaf/hard of hearing children in B.C.

BC Hands and Voices is a registered charity (Charity Registration Number: 83838-4428 RR0001).

To make a donation, please issue a cheque to BC Hands and Voices, and mail to:

1965 Rodger Avenue, Coquitlam, BC V3C 1B8.

A tax deduction receipt will be issued for any donation of \$25 or more.

BC Hands & Voices is a parent-driven, non-profit organization dedicated to supporting families with children who are D/deaf or hard of hearing. We are a parent/professional collaborative group that is unbiased towards communication modes and methods, believing that families will make the best choices for their child if they have access to good information and support. Our goal is to support families in achieving successful outcomes for their children.

#### Contact us via email:

# info@bchandsandvoices.com

Visit our website:

## bchandsandvoices.com

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