BC HANDS & VOICES

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BC Hands & Voices is a parent-driven, non-profit organization dedicated to supporting families with children who are 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.

Tarron’s Adventures in the Wild

By Lynnea Stacey, Fort St. John, BC

The Wild Staceys, that's us. It came from the Tarron’s favourite TV show, Wild Kratts. He wanted to have his whole family be Wild Staceys because it meant we would always be together -we were a team. It began to stick when he told us "We are The Wild Staceys…and we will do wonderful things." Well it made my heart swell, this wonderful boy... who loves so deeply, and feels so strongly.

It hasn't always been easy, in fact it rarely has! It’s been scary and confusing. How could this happen?

I brought Tarron, my fourth baby, home from the hospital. Born six years after my last baby, he was the missing piece of our family. By the time he was 4 months old, I knew something was up with his hearing. I had to push for it but we scheduled a hearing test in the nearest city to our wee town in northeastern British Columbia, Fort St John. Unfortunatley, the sound booth there is set up for adults, not babies, and we got no information. Instead, we had to wait five months before Tarron was scheduled for further testing, this time an auditory brain response (ABR) and an MRI, at the Children's Hospital in Edmonton, Alberta. Edmonton is a nine hour drive for us.

We couldn’t have been more shocked when a man came into our waiting room and said in no uncertain terms “Your son is profoundly deaf. Both ears. Any questions?’ We were stunned. What? Our son? How can that be? He then told us to wait in another room where an ENT specialist would come see us. This doctor explained to us about Tarron’s hearing loss and told us that he would be a candidate for a cochlear implant. “Oh and by the way.... You will now have to travel to Vancouver and have all these tests redone and have him reassessed as you’re from British Columbia and we can’t cross provincial heath borders. Any questions? No? OK, bye, have a nice trip home...”

I remember crying in our truck.

I remember my husband staring at the road, not talking.

I remember our cell phones ringing, and shutting them off because we couldn’t say it out loud to anyone.

I remember seeing my beautiful boy smile at me.

I remember talking to him and then stopping because I now knew he couldn’t hear my voice.

I remember crying more.

That night we sat in our hotel room and tried to come to terms with all this news. I had to learn to let go of the child I thought I had had and embrace the one we did have. We had to change our path...and I became fiercely protective. I live in a very small town and gossip and rumours can rule. Being different is usually not a good thing here. Now Tarron was the only deaf child in our community.

We finally turned our phones on and talked to our families. We asked them not to say anything just yet to other people. It was only after we had done our research and felt confident with the information that we began to tell our friends; the news spread like wild fire.

Adventures in Sign Language

Shortly after his first birthday, it was decided that Tarron could receive a cochlear implant. During the assessment period leading up to this, though, we learned to sign and dealt with hearing aids. Some family learned sign along with us and others relied on us to communicate with Tarron – we made each person's choice work. Although I mourned the loss of no baby chatter and hearing him say mama for the first time, I learned that a baby signing is pretty much the sweetest thing you have ever seen:

I would be trying out some of my new sign words while shopping in our tiny grocery store when people would come up and start finger spelling to Tarron. He would look at them – blankly- and they would say "Oh, he doesn't sign yet?". "Well, yes, he is learning to sign but at not even a year old he hasn't mastered spelling!"

One day when I was shopping a lady came up to me to tell me how beautiful my baby was, and to ask what was wrong with him. "Oh nothing is wrong with him, he is just deaf", I replied. "Oh I figured it was something, God made him extra beautiful to make up for his ears.". Well I didn't quite know how to take that - Thank you, I think!

Adventures with Cochlear Implants

We have a deaf friend who is 100 percent against cochlear implants. He came to our house so furious with us for even considering such a thing. He told us all kinds of horror stories his fellow deaf friends had told him. This was one of the hardest parts… the doubt. Is this the right thing for Tarron? We were lucky to have been involved with BC Family Hearing Centre in Vancouver: they were our life link at this point, supporting us through our learning and decision making.

After Tarron's surgery when he was 21 mos old, we started on the road of Tarron's habilitation. We learned about his equipment, attended speech therapy in Ft St John and online, and traveled to BC Family Hearing Centre and BC Children's hospital in Vancouver. We had a box of spare parts that we had to pay to have replaced often because Tarron loved to chew cables and coils, throw the implant during tantrums or simply not notice when he lost it. So many heart stopping moments when you realized he was not wearing his implant. Backtracking and hunting…once on a snow covered hill, many times in our house and vehicle. Then came the phase of taking it off and purposefully "losing it". We even found it attached to the side of the stove after he discovered the magnet would jump to the metal if he got close enough. All this was done with a nonverbal kid who wouldn't tell you where he had left it. He just shrugged "I don't know!" We used clips and cables and cords and invented some of our own. We had friends and family trained to check if the implant was on, and it did eventually get better.

Four years after his initial surgery, we were told at long last that Tarron could get a second cochlear implant. And so a whole new series of visits to Vancouver began. To this day, we travel to Vancouver twice a year. We now love going there, and we do our best to fit in some fun between the mapping and check-ups – sushi and Granville Island Tea are highlights!

Adventures at School

When he was ready to start Kindergarten at age 6, we decided to move to the largest city in Northern British Columbia, Prince George, to give Tarron the best start in school that we could. Here, he would have access to a deaf community and other kids who had similar equipment as his. This was huge because, unless we were in Vancouver, Tarron never saw another child with a hearing device; he was alone in our town.

After a year, however, we returned to our home town for Tarron's Grade 1. It was a great experience to live in Prince George but my daughter wanted to graduate with her old classmates, and my husband was still working there; we were traveling back and forth four hours to see each other. Plus, we still owned our home there and were renting in Prince George. It was a difficult decision but we remain connected with our Prince George community, attending many of the Deaf society events.

Tarron now sees his Teacher of the deaf and hard of hearing every other Friday, and he has a part-time Educational Assistant. I also work at his school and can volunteer in his class. Nevertheless, he can face some challenges as the only deaf child in a small school.

For example, one day when I was in his classroom, Tarron's batteries died and we didn't have his spares. The other kids crowded round, yelling "Tarron can you hear me?? Tarron!!". They also tried what some sign they'd learned. They ended up shouting and signing"SIT DOWN!" Tarron looked like he was going to burst into tears. After calming him down outside the classroom, we decided to leave.

The plus side of this experience was that Tarron's deaf/hh teacher started a classroom program to show them what it can be like to be deaf. She took kids out of the classroom in small groups and had one child at a time wear sound-canceling headphones. She had them do a spelling test and, after they were done, she would tell the kids a joke. Then the hearing kids would laugh. After she would ask the child in headphones what it felt like, and they all said they thought she was talking about them and laughing. It was a valuable lesson for them to learn what Tarron's life was like.

Currently, Tarron is thriving halfway through Grade 2. Creative writing is his favorite subject. He speaks very well and is self-sufficient, looking after his own equipment and batteries. He is still reliant on the "old ear", the one that was first implanted, but says "baby ear" sounds almost exactly the same now. I've persisted with signing to him throughout all of these transitions. After a downturn in his signing after school started, he's expressing more interest in signing again, so this remains a future goal.

Throughout all of these adventures, he remains our wild boy – you'll find him playing hockey, soccer, or running with his big brother and dad. He wants to be a great hunter "as soon as I am as big as they are." Which is happening way too fast for me.

It Takes a Community to Raise a Deaf/Hard of Hearing Child

And Other Lessons Learned From the 2013 BC Hands & Voices Workshop

By Jen Gow, North Vancouver, BC

This year's BC Hands & Voices Fall Workshop was the third that we have attended.

Our first was in 2011, just after we had found out about Connie's profound hearing loss. It was our introduction to a new community. The focus on siblings of children with hearing loss wasn't hugely relevant to us at that time, as Connie was a babe in arms; squabbling with Rowan, her big sister, seemed a long way off. However, the opportunity to meet other parents of deaf/hard of hearing (d/hh) children and, in particular, to meet d/hh adult role models was invaluable to us.

The 2012 Workshop "Keeping Your Eye on the Prize: Inspiring Stories from Young D/HH Adults" was also a great learning experience for us. We have regular opportunities to meet with other d/hh children and their parents, and to connect with d/hh adults, but the demographic of this workshop panel was our missing link. These young adults were all inspirational in their choices and achievements, and they gave us real insight into what it was like to grow up d/hh, and how it continues to influence their lives now.

This year's Workshop, entitled "Parent to Parent – Sharing the Wisdom" was, in many ways, a natural extension of last year's topic, as we got to hear from parents of older d/hh children. The panelists represented a diverse set of families; the age of the their d/hh children ranged from Kindergarten to young adults; and the level of hearing loss varied from mild to profound, with some children Deaf and others assisted with hearing aids and/or cochlear implants. The discussions centered around questions such as: What is it like raising a d/hh family? What lessons have you learned about you child, yourself and your community support system? What do you know now that you wish you'd known from the start?

Always welcomed with open arms at BC Hands & Voices events, this year we felt like we'd crossed a bridge from being newbies to veterans! We were reunited with friends and familiar faces, as well as having the opportunity to meet new families. This aspect of the Workshops is as important to us as the topics themselves. Indeed, the importance of having such a peer group was driven home by the parent panelists themselves, many of whom felt that the strongest support they had received came from other d/hh families. This has often been our personal experience, but we were a little surprised to hear that it is more common. After all, wouldn't most people hope to receive the strongest support from their closest family and friends? On the other hand, parents of d/hh children have more closely shared our own experiences and will likely have a deep understanding of the issues we have faced. This not only validated the importance of this community to our family, but also allowed us to be kinder on those close to us who haven't always been able to offer the same level of understanding.

Several other key points have stayed with us in the months since the Workshop. The lessons that we take home from each event mainly depend on where we are on Connie's journey at that time, and we're sure that other attendees will have remembered different points that were particularly relevant to their family's situation. That said, some of the lessons that stuck with us are important for all our families to consider:

- Give your child opportunities to connect with their d/hh peers and role models. The childcare available to us during the event was one such excellent opportunity. Thanks to Joy Santos, a cleverly adapted room provided a fun facility for our little ones. The qualified caregivers were fantastic at keeping the children happily occupied – even my stranger-shy Connie settled in and enjoyed her day, which is high praise indeed!

- Incorporate rest time into your d/hh child's day to minimize the impact of concentration fatigue. Communicating can be tiring for them, and we need to respect their additional need to relax by, e.g., offering them a quiet house, a nap, some solitude or a peaceful walk.

- Knowing how to communicate most effectively with our d/hh children is not an innate skill but a learned one. It can seem hard to adapt to the changes as we learn these skills but eventually they do become second nature.

- Likewise, it's important to learn how to advocate wisely for your child's needs. As well as passion, this needs diplomacy skills – bridges burnt with professionals today may return to haunt you if your paths cross in the future (which is quite likely in this small, tight-knit community).

We're trying to incorporate these lessons into our lives, bearing them in mind as we continue on our journey with Connie, facing novel situations and decisions. This year, Connie will transition from toddler to pre-schooler; we look forward to what words of wisdom we'll pick up from the 2014 Workshop.

Please “Like” us on Facebook

Our Facebook page is booming!! We have grown from 66 "likes" to 100 "likes" in a very short time and we are coming up with new ideas to make our page informative, interactive, inspirational and current :)

Signing Time on Netflix!

This instructional series, hosted by Rachel Coleman, introduces children ages 1-8 to American Sign Language (ASL). Episodes of the series are now in the Netflix catalog.

Art & Inspiration Corner

“Year of the Horse” by Skyla Foo

"Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence." -Helen Keller

Fun Family Picnic

Saturday June 14, 2014

an event for deaf/hard of hearing
children, their siblings and parents
and children with their Deaf/hard
of hearing parents (CODA)

11:00 am to 3:00 pm
at Provincial Deaf and Hard of Hearing Services
4334 Victory St., Burnaby

Registration:
Pre-registration is required so we know how many people to expect! REGISTER ONLINE by June 6 at www.CHHAparents.com

Hosted by:
BC Hands and Voices
Guide By Your Side Program
CHHA BC Parents' Branch
Family and Community Services
Family Network for Deaf Children

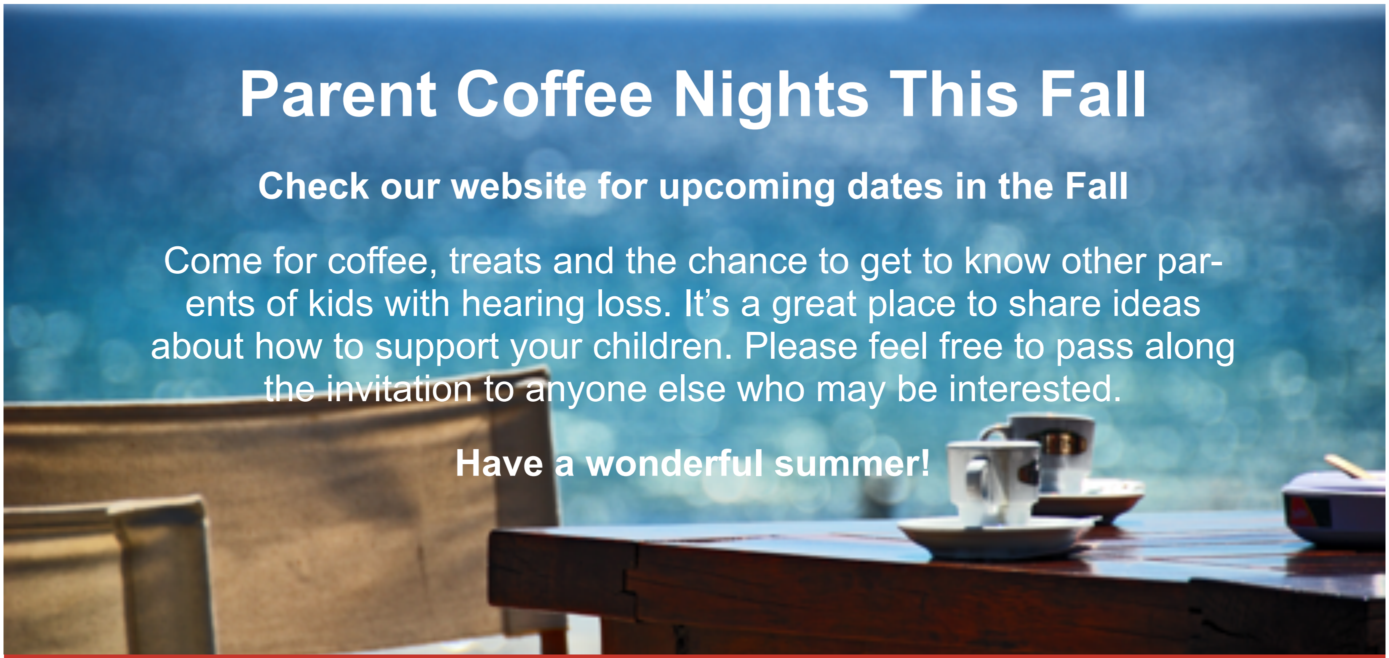
Parking:
Parking is available on Victory Street and on McKay Avenue

We will provide:
- Hot dog lunch
- Entertainment and games
- An opportunity to mix & mingle with other families and with youth/young adults who are deaf and hard of hearing.

Please bring with you:
- a dessert to share (note no freezer/fridge/oven)
- drinks for your family (No alcohol, please)
- lawn chairs or blanket to sit on

Rain or Shine! Free admission! Donations gratefully accepted.

Register today at www.CHHAparents.com



Parent Coffee Nights This Fall

Check our website for upcoming dates in the Fall

Come for coffee, treats and the chance to get to know other parents of kids with hearing loss. It's a great place to share ideas about how to support your children. Please feel free to pass along the invitation to anyone else who may be interested.

Have a wonderful summer!

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 BC. 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.

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Contact us via email: info@bchandsandvoices.com

Visit our website: bchandsandvoices.com