

BC HANDS & VOICES

September 2011 - Issue No. 8



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.

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

One Family's Journey

When My Daughter Made Her First Ling Sound

By Gina Cooper

Our daughter Sara was born profoundly deaf in both ears in June of 2009. She failed the routine hospital newborn hearing screening test and was subsequently referred to our local hearing clinic for follow-up tests. After months of inconclusive results, Sara was finally given a sedated ABR (Auditory Brainstem Response) test which confirmed bilateral profound hearing loss.

We were quickly teamed up with a brilliant Teacher of the Deaf & Hard of Hearing, a Speech & Language Pathologist, Infant Development Worker, and wonderful Social Worker here in Victo-

ria, BC. Sara was immediately given hearing aids, which we were told would get her used to wearing equipment on her ears, but would not do much in the way of giving her enough access to sounds to enable her to speak effectively. Wearing the hearing aids would prepare her for a cochlear implant, if we decided to go that direction.

My partner and I extensively researched various communication methods, interviewed available outreach services, and talked with many people about whether to incorporate sign language.



Sara smiles by her name

We also researched the deaf community because we were conflicted for awhile as to whether we actually wanted to implant Sara. Our thinking was that if our daughter was put on this earth as a deaf human being, maybe she is meant to be raised without a cochlear implant. That phase passed as we learned how truly effective the bionic ear is in enabling a deaf person to hear sounds and learn to speak clearly. We eventually chose a specialized agency for outreach service, and decided on a Total Communication Method, which utilized ASL along with auditory/verbal therapy. Our personal belief is that our child would need a solid foundation of sign language coupled with a cochlear implant. If the CI is ever lost or not working, we believe she should have a communication method to fall back on and sign language would surely be her mother tongue as a deaf person.

In early March of 2010, we started signing to Sara...the basics that go hand-in-hand with daily routines such as 'eat', 'drink', 'more', 'change diaper', 'sleep', and more. Also, I would take long daily walks and point out and make the signs for 'bird', 'tree', 'grass', 'water', 'sky', 'sun'. It seemed like forever until Sara made her first sign. About three months later, she offered a cute rendition of 'bird' that just brought tears to my eyes!

Sara was then implanted with a Nucleus 5™ Cochlear Implant in September of 2010, with switch on in October. I was told that it might be a challenge for the first little while with getting her to want to wear her CI, but that it was very child-specific.

If EVER a challenge was thrown out to me, it was during the first three months after switch on...the work, the effort...from morning to night...I thought, at times, I would lose my mind.

Struggling for twenty minutes with an extremely head-strong toddler, just to put the CI on Sara's head, only to have her rip it off and throw it across the room. Trying, with all my might, to control my frustration, sadness and sometimes anger, keep a smile on my face, make it a fun experience...when all I really wanted to do was put the stupid thing through a wood chipper and raise my daughter with sign language and no CI. I can remember standing in the living room one afternoon, after a morning full of temper tantrums and a processor that got chucked somewhere, now lost, and literally breaking down into a sobbing mess. My child watched as I curled up in ball on the floor, feeling totally helpless. God...how do I do this? No, seriously...how do I do this!

Just before retiring for bed that night, the song "Let It Be" by the Beatles entered my mind. There will be an answer...just 'let it be'.

My mind had become a cesspool of worry, obsessively reading books on therapy methods, having non-communication nightmares, feeling almost agoraphobic some days at the thought of taking Sara to a 'normal' playgroup where we would attract attention due to the CI. I was starting to lose sleep, and my anxiety was getting the better of me. To be honest, on this day, I wanted to run away. I wanted to do an 'ostrich' and have someone else teach Sara to talk. I was feeling burdened. So, as I drifted off to sleep, I played 'Let It Be' over and over in my head. Around midnight, I awoke to Sara crying, so I leapt out of bed, collected her from her toddler bed in her own room and returned her to our family bed to spend the rest of the night. As I nursed her back to sleep I suddenly recalled that I had just been dreaming....not a nightmare, but a sort of epiphany-like dream.

In my dream, it was as though I was on an archaeological dig, chipping away at a wall. I knew that I needed to work hard at this wall and that something would be revealed. I had grown exhausted, both emotionally and mentally, as this wall just would not give. In fact it seemed hopeless. The frustration was making me grow resentful. I finally gave one last concerted effort, then stood back and just stared at this blank wall. Suddenly, a tiny piece broke away, fell to the floor, and

an illuminating brightness appeared. I couldn't see exactly what it was, just that it was the kind of light that was inviting, motivating and inspiring! I got a second wind to get back to work with a renewed vigour and ENTHUSIASM! I returned to my work, in a new way and wouldn't you know it...this beautiful piece of artwork began to emerge...so breathtaking, it left me awestruck.

The next day I thought to try a new therapy method by putting Sara in the baby backpack, where she would be a 'captive recipient', and going for a walk down to the water. Why didn't I think of this before! Sara loves the outdoors, (her first sign she learned was 'bird), I can tie a hat on her head so she can't rip the CI off and I can talk to her practically head to head! Win/win situation.

The following week, our therapist continued in her efforts to teach Sara the ling sound of 'ahh' in association with a toy airplane. Out of the blue, Sara picked up the airplane and made her first sound of 'ahhh'! She then said 'ahhh' without a prompt from the therapist. Goosebumps!!

I had envisioned myself crying for joy when Sara made her first sound. But I didn't cry. What happened was I heard for myself my daughter using her voice. In that moment, the bricks of worry fell hard to the ground and shattered into a million pieces. The confidence in the equipment, in

Fraser Valley FiT Network Society

A Social Network created to keep Special Needs 'Families in Touch.' Monthly FIT Meets, Seasonal Family Fun Events and Casual Coffee nights provide opportunities for parents with special needs children to 'Get FiT'* - *Families in Touch

For families from all over the Lower Mainland. If you want to Get 'FiT' check out our website at fitnetworksociety.com or email Hayley Nimmo at fitnetwork@live.ca

"In the 2 years that our family has been involved with the FIT Network, we have attended family fun events where we connect with other families with children with special needs; siblings are able to meet, play and learn that they are not the only one that has a brother or sister with additional needs. I have also really enjoyed attending monthly meetings with amazing speakers and discussion around topics such as how to be prepared for your child's IEP, alternative therapies, behavioral strategies and sexual education as it pertains to children with disabilities. Some of the best information I have received has come from the experience and knowledge shared by other parents." --- Kim Shauer, parent.



BC Hands and Voices is now on Facebook!

"Like" us on Facebook and be informed of upcoming workshops, family events, and other great opportunities to network.

facebook.com/handsandvoicesBC



the therapy process, in my daughter's brain, finally took root. I had an experience and I moved beyond just believing that the sound was getting to her brain, that the Nucleus 5 was indeed working properly, that the therapy EVERYONE was doing was effective...I now KNEW!

I videotaped this breakthrough and a few people told me that Sara would now skyrocket (though slow and steady) with her speech development. Sara is now vocalizing every day, for longer periods of time and leaving her CI on because she has finally realized what it is for and is receiving benefit from it!

Since then I have found more and more 'win/win' therapy methods, where I am not forcing therapy on her but instead either going to her whenever she is naturally involved in something — like bathing (so many great sounds to bring her attention to and have fun with like bubbles, the tap

running, water splashing, rubber duckies and fishies, washing the hair, etc.), or placing her in a therapy situation with something that I know she will enjoy...like feeding her ice-cream in her highchair after dinner and working on the ling sound of 'mmm' with the word 'yum'!!!

Sara also enjoys helping with the laundry, so I let her put the clothes in the washer, turn it on and point to the machine as she watches the clothes go around and hears the sound of the water rushing in. The sign for 'wash clothes' is a pretty neat one too that requires a fair bit of coordination! I also take advantage of car rides, especially travelling to and from the mainland. Ferry line ups used to be a major source of stress as Sara doesn't like to sit in her car seat for long periods of time. I figured out that I could perform a hand-puppet show from the front seat and make all sorts of sounds and send

her into giggle fits. Once again, she is a captive therapy recipient, and it is FUN for both of us!

Now, I use my imagination a lot to try and find any opportunity to make meaning of sounds, and am very animated and expressive with the little things so that I can capture her interest and keep her entertained. This the most amazing process to be involved with. It is very tiring at times, yet so thrilling, so emotionally-charged, so incredible to watch and hear. It is simply a miracle that our deaf child can learn to hear and speak with this piece of technology called a cochlear implant. Gratitude seems like too small of a word. God, The Universe-- whatever you wish to call that higher power-- is, to me, truly awesome!

Editor's note: Excerpted and adapted with permission from the author's Blog: SoundsForSara.blogspot.com

Thank You



We would also like to thank Hazel Weeds for her donation in memory of her daughter, Diane Goodman (pictured at left).

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

Third Annual Fall Parent Workshop



Saturday, October 22nd
10 am to 3 pm
BC Family Hearing Resource Centre
15220 – 92nd Avenue, Surrey
\$10 per adult, kids free. Lunch included.
PAY AT THE DOOR



Brothers & Sisters:

Encouraging Healthy Relationships Within the Family

Presented by: Angela Clancy, Executive Director of the Family Support Institute

Meeting the needs of everyone in the family can be a challenge – especially when one or more of the children are deaf or hard of hearing. This interactive workshop will focus on identifying common issues that arise with siblings, as well as strategies, ideas, and resources to help deal with them. There will also be time throughout the day for families to socialize and share information with one another informally.



Topics will include:

- The needs of all children
- Sibling relationships
- Parenting strategies (active listening and overall effective communication)
- Dealing with conflict
- The benefits of growing up with a brother or sister who is deaf or hard of hearing



DO YOU LIVE OUTSIDE THE LOWER MAINLAND?

We have a travel grant from BCCH to help cover travel expenses for families.

Contact us for details.



REGISTER by Wednesday, October 12th

Online at www.bchandsandvoices.com or email info@bchandsandvoices.com

- Childcare will be provided at no cost but children must be pre-registered.
 - ASL interpreting will be provided.
 - Language interpreting may be available for families who do not speak English.
 - Contact us ASAP if you know of a family that requires interpreting. Resources are limited.
- Call BC Hands & Voices at 604-552-2254 with any questions**

The Best Fit for One Family

By Joy Amor

“Baby Sign Language is all the rage nowadays!” I exclaimed to myself as I finalized my order on Amazon.ca for Baby Sign Language books and DVDs. I was six months pregnant, and like any other new (and nervous!) mother, I had spent massive amounts of time on an endless quest for information, tips, and latest trends in parenting. I aspired to raise an imaginative and articulate child, and often fantasized of someday having a conversation with my toddler where he or she would tell me stories about their day at preschool, and I was especially looking forward to hearing the ones drawn from the imagination. All my research seemed to suggest the same con-



cept to “Introduce language to your child at an early age.” So it was then that I made the decision to commit to ensuring that my child would be in a language enriched environment, be it spoken or visual. My DVDs and books had finally come in, I was excited! About five minutes into watching my first DVD, I was already confused. The woman on the television seemed to just be making random hand gestures, and I thought to myself, “This is all supposed to mean something?!” I made sure I knew the *basics*... “Milk,” “Diaper,” “Bath,” “More,” and “Sleep.” I felt that was enough visual language to let my child know I was making an effort to communicate. Besides, I thought that making sure that I constantly spoke to my child would still be promoting a language enriched environment. Alas, like any other impulse online purchase, the books and DVDs collected dust. Early Halloween morning, Teanna was born, and she instantly had me wrapped around her tiny little finger. Yes, I was smitten, and I wanted to give her the world. She was a tiny girl, yet in spite of her petiteness, it was already ap-

parent that she had a big and captivating personality. Even as an infant, she seemed to be extremely observant, her eyes wide, a naturally curious expression, and her head constantly turning as if to absorb everything going on in her surroundings. I spoke, sang, and signed the very limited amount of signs I knew with my daughter. She smiled and giggled no matter what I did, she was a happy child, and I, a sleep deprived but nevertheless happy mom. At 8 months old, she signed “diaper,” and when checked, had actually needed a diaper change. I was floored, to say the very least – my child was communicating! At 10 months, she had learned to sign “sleep,” and I would have to gloatingly say that bedtime was *always* such a breeze. I loved her, and I was happy, but there was a part of me

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that felt like there was something that was not quite right.

By the time Teanna had turned a year old, she was happy and healthy as ever. However, there still seemed to be some sort of disconnect, a gnawing feeling, if you will. I have had suspicions regarding her hearing since she was born, and it was not until she was 19 months old that she was officially diagnosed to have been profoundly Deaf in both ears. It was a rough and emotional experience, and not only had I felt like I was mourning the loss of something very important, but I was also lost as to what to do next. It was an overwhelming time, filled with so much information from a multitude of resources. It was a time for life-altering and time-sensitive decision making, and frankly, I had begun to feel so numb from it all, that it felt like I was simply being carried along the chain of events.

Teanna had immediately gotten fitted for hearing aids, and I felt it was the best decision to choose an intervention program where both a Sign Language Instructor and Speech Language Pathologist would be available. Having an actual instructor for American Sign Language (ASL) made learning it easier. I discovered just how visual the language is, as most of the signs are reminiscent of the English word definition. It definitely was *not* just a “bunch of random gestures” made in an effort to convey a thought. ASL is an *actual* language, with gram-

matical rules that needed to be followed. As much as I found the learning process enjoyable, it took some time for me to feel comfortable using it, even with the instructor. However, as unnatural as it felt, I knew that it would benefit my daughter, so I made an effort to sign with her as much as I could when it was just the two of us. There were many aspects of ASL where I felt slightly awkward. One example being the use of very pronounced, almost exaggerated facial expressions. Raised eyebrows when asking a yes or no question, a furrowed one when asking one that needed a more detailed reply. Pursed lips when describing something that is small, and saying “cha!” with eyes wide to describe something large. It was a time of adjustment.

As with most languages, ASL was accompanied by a culture of its own, the *Deaf Culture*. Throughout my journey, I have come to learn that Deafies are a very warm and welcoming bunch. I was noticing Deaf people everywhere! I would muster up the courage to approach them in restaurants, at the mall, and I had even found a church that had a Deaf ministry. I had mastered signing, “Hi, my name is Joy. I saw you signing, are you Deaf? I have a daughter who is Deaf, and I am learning Sign Language very slowly.” When a Deaf person sees you making an effort to communicate in their language, their eyes light up, and they are

more than willing to sign extra slowly, or even try and speak to have a conversation with you. It was a great feeling when I saw that I, a hearing person, could have a sensible conversation with a Deaf person. In the Deaf Culture there is Deaf Pride, which states that a Deaf person can do anything except hear. I found the culture to be extremely interesting, and begun to immerse myself in it at my own time. I read books, articles, and websites – I wanted to be educated, after all, this *IS* my daughter’s culture.

Teanna received a Cochlear Implant in her right ear in the Winter of 2009. She currently goes to a preschool where both Deaf children, and children of Deaf adults (CODA’s) attend. In school, the teachers both sign and speak. She receives Speech Therapy everyday, and is showing steady progress, as she is currently babbling and making great efforts to speak certain words. She is also recognizing various words that she hears. Her Sign Language skills continue to impress me, she is becoming quite fluent, and at times I feel like I am starting to trail behind. Through Sign Language I can see that she is clever. “I want juice, please,” she asked me one day. “I don’t have juice for you right now, just water,” was my reply. She held up a grape that she was snacking on and signed, “Ok, there is juice inside the grape,” then ran off to play. Through Sign language I can see that she has a sense of hu-

mour, she jokes around and I know what types of things she finds funny. Currently she has many imaginative stories involving slapstick comedy. Through Sign Language she is able to voice her emotions, recall past events, and express what she hopes to do in the future.

Personally, the decision to give my daughter a combination of the Cochlear Implant, speech, and American Sign Language is what works for us. There is no doubt that it keeps the calendar pretty full, but it also poses plenty of perks. Teanna will be bilingual, and I feel that she is able to receive the best of what being Deaf

and hearing has to offer. Growing up, I lived an expatriate childhood, and I would constantly be reminded that it is important to “remember my roots.” I believe that the decision to educate and involve ourselves with Deaf Culture is giving my daughter a solid foundation as to who and what she is. It is a fact that I am raising a Deaf child in a world that is predominantly hearing. Being involved in the Deaf Community gives her a sense of belonging, and surrounds her with people with whom she shares something in common. I believe it is this involvement that will give her a strong sense of self, thus giving

her the confidence to venture out into the hearing world. Teanna will be faced with having to make various decisions about her life as an adult. With the foundation that I am laying out for her, I strongly believe that I am giving her all the tools she may need, no matter which path she chooses. I too, am preparing myself to be in a position to support her decisions. When she was born and I held her for the first time, I knew I wanted to give her the world... Now, she has both the Deaf and hearing worlds at her fingertips.

Wig Tape and Hand Sanitizer

By Cheryl Lacey

It was a few years ago now, when my eldest son was approaching three, that a close friend of mine invited us to her son’s birthday party at a play place. To this day I have a love-hate relationship with these places! Kids love them but they cause me ‘equipment angst’ half the time. Our son had been implanted for about 6 months and keeping the cochlear implant (CI) on was proving to be a challenge so I decided to try the wig tape trick. About 30 minutes into the drive I look back and my son has his CI off and is pulling at a clump of hair on the crown of his head – the wig tape! Great I thought; how will I get this clump of goo out when we’re headed off to a play place? When we arrived, the owner of the play place promptly suggested I try using the hand sanitizer. Not 2 seconds later, it was out without a tear to be had! I have continued to use hand sanitizer on such sticky occasions; it even works great to get tree sap off of sticky feet when camping. Just a neat little trick discovered on the journey of raising kids with hearing loss!

A Change in Direction...

By Paula Jensen



My husband and I have two daughters with normal hearing, and a son who is hard of hearing. Our son Cole was diagnosed with a moderate-severe, bilateral, sensorineural hearing loss when he was almost 4 years old. He wears two *behind-the-ear* hearing aids, and gets a great benefit from them. Due to his late diagnosis, we recognized the need to act quickly and investigated all of our options for early intervention programs. We decided on the program that we felt most closely matched Cole's needs and our family's beliefs. Our goal for Cole has always been that he attends the mainstream public elementary school in our neighbourhood catchment, along with his older sisters.

Cole spent two years in a full time program. He responded very well to the methods that the teachers used. We marvelled at how bright he was, and how his personality blossomed once he learned how to express himself and communicate with other people. When he first started in the program, his language skills were below average compared to hearing kids his

age. Just one year later, he was well above the average. At the end of each day when I would pick him up, I was able to chat with his teacher for a minute or two. Those little conversations with his teacher were invaluable to us as parents, and allowed us to feel connected to the teachers, and the classroom, and just to know what was going on in my son's world. He learned so much from the teachers, and we also learned how to best support him at home with his new language & vocabulary. Cole continued to do well in Kindergarten in the program, and he was reading above grade level by the end of the year. Needless to say, we were very pleased with the progress he had made during his time in the program.

When Cole finished Kindergarten, we decided that he was ready to enter the mainstream school system. We had heard about an elementary school within our school district that also offered extra support for deaf/hard of hearing students. We visited the school and thought it seemed like a good "stepping stone" for Cole.

He was excited to go to a new school, particularly because it meant that he would get to ride the school bus! We decided to enrol him at the school for Grade One, and then transfer him to our neighbourhood (catchment) school for Grade Two. So that September, he started in Grade One and things were going well. I communicated with his classroom teacher & support workers, and they all reported that he was adjusting and doing well. After about three months, we started getting phone calls from Cole's teacher about his behaviour. Most of what was being reported to us was typical behaviour for a six year old boy. We talked with Cole about it, but it was difficult to discipline him for behaviours that we never saw him doing at home. Cole rode the bus to school, so I wasn't able to be at the school every day, like I was at the program. This created a bit of a communication issue between his teacher and home. I felt that we didn't really know exactly what was going on with him, and had to keep asking for information about his progress. We met

with his teacher to try & resolve these issues, but we came away still feeling unsettled. We weren't getting what we needed. We decided that rather than putting our energy into fixing the issues at his school, we would work on finding out what was involved in transferring him to our neighbourhood elementary school. We weighed the pros and cons of moving him in the middle of the school year. One of the cons was that the level of support he would receive would be less than he was used to. We knew that he was doing well, but wondered if he would continue to thrive with less support. We also worried about how classroom life would be for him, as he had been through a lot of changes in the past few years. One of the pros was that I would be able to visit his classroom at any time during the day, because I was close by. That regular contact with his teacher & support workers made a world of difference in our comfort level. I met with the Principal at our neighbourhood school to discuss Cole's current situation

and the possibility of transferring him to that school. She was very accommodating and said they could take him right away. She made it clear that she would do everything she could to make sure Cole got the support that he needed. So, in January, we made the decision to transfer him to our neighbourhood school. In true Cole style, he settled in easily, made friends and did very well academically. His teacher was very impressed with how much language & vocabulary Cole already had, and said that he had been teaching her all about electricity! One of the things that we learned from this process is that even though you have done all the research, compared your options and made the best possible decision for your child, you won't always have a perfect outcome. Some things are out of our control, and we never know how things will go for our child until we try it out. There is no shame in trying. If I had it to do over again, would I change anything? Probably not. I

still feel we made the best decisions with the information that we had at the time. The fact that everything didn't work out exactly as we had hoped is just part of life! Parents make decisions for their children every day. It's important to remember that we are not locked in to those decisions. It's okay to make a change if the situation isn't a good match. It doesn't mean that we've failed; it just means that we need to make an adjustment to our path. We all know our child best, better even than some of the professionals, so trust yourself to make those decisions for your child...the decision must FEEL right. *What works for your child is what makes the choice right*

Did You Lose a Bowl?

Lost and Found!

Did anyone leave a nice bowl at the Spring Picnic?

The bowl is with Cathy Luther now.

Please contact Cathy at cathylouise@shaw.ca to get it back.

Hands & Voices Spring Picnic 2011

By Teresa Kazemir

BC Hands & Voices hosted our third annual Spring Picnic on Saturday May 28, 2011. It was a great success, with 80 people in attendance (23 families).

We were able to rent a hall for the first time this year (Clayton Hall, in Surrey). In the past we have had only tarps or a picnic shelter, and we have had three picnics in the pouring rain. This year it was cold and damp in the morning, so we started out inside the hall, which was a great place to eat and do crafts. Then, as the sun came out, we moved outside to the playground for some games and a piñata. It turned out to be a lovely day.

The kids loved the face painter/balloon artist we hired, and the two student volunteers (Marina Rasmussen and Amar Mangat) were fabulous. Everyone enjoyed the food, as always, and parents had an informal opportunity to chat and connect.

Thank you to:

- BC Early Hearing Program for providing funds which allowed us to rent a hall
- Preferred Interpreters, Inc., for providing interpreting for our event at no cost
- BC Children's Hospital – their grant allowed us to hire the face painter/balloon artist, and also to offer the travel grant to families wanting to travel from outside the Lower Mainland



Photos courtesy of BC Hands & Voices Dads Ron Preer and Steve Kazemir

Donate Now

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

To make a donation, please issue a cheque to BC Hands and Voices, and mail to:
BC Hands and Voices
5513 Parker Ave
Victoria, BC V8Y 2N2

A tax deduction receipt will be issued for any donation of \$25 or above. BC Hands and Voices is a registered charity (Charity Registration Number: 83838-4428 RR0001).



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Contact us via email:

info@bchandsandvoices.com

Visit our website:

bchandsandvoices.com

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