

BC HANDS & VOICES



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.

Bilateral BAHAs

Is Bilateral Better?

By Teresa and Jesse Kazemir

After using a Bone Anchored Hearing Aid (BAHA) for 6 years, our 14 year old son Jesse recently received his second BAHA – he “went bilateral.” He was born with bilateral atresia (no ear canals or openings on either side) and has a bilateral severe to moderate conductive hearing loss.

In spite of having **bilateral** atresia and **bilateral** hearing loss, Jesse wore just one hearing aid for the first 14 years of his life, and for the most part it worked out well. He had a bone conduction hearing aid until he was 8, when he was fitted with his first BAHA (after two surgeries to implant the titanium screw and “abutment”). Jesse has always used an FM system in school, and has done very well. Listening in noise was (and is) challenging, but Jesse has always seemed to hear better than we expected him to, given his hearing loss. As long as we got his attention first, he seemed to be able to hear us over the background noise, and when that didn’t work, we used a little sign language as a back-up.

While Jesse did well, we always wondered if life would be easier for him if he had bilateral hearing aids. For one thing, having a single hearing aid is a real pain when it breaks. He would either have to use his old



bone conduction aid, which he no longer liked after getting the BAHA, or we would have to fit in an urgent trip to the audiologist to get a loaner. Secondly, Jesse had practically no ability to localize where a sound was coming from. When he was little, we were always concerned for him around traffic and in parking lots. And then he always had a “good side” and a “bad side,” and I have never been good about remembering to sit on the good side of him – and, to be honest, I always had to concentrate to remember which side his BAHA was even on! Lastly, and perhaps most importantly to Jesse, were issues related to music. Jesse is a great fiddler, and plays in a Celtic Ensemble with twenty other teens. With one hearing aid, which is situated very close to his violin, he often has difficulty hearing the guitar or the other fiddlers over the sound of his own violin. We wondered if having a hearing aid (and

thus microphone) on the opposite side would allow him to hear his fellow musicians more easily.

So, we sat down with Jesse to see what he thought about the whole idea. He was not too keen on the idea of another surgery (he has also had two other unrelated surgeries) and in general didn't really want to get it. However, we talked with a few people, including his audiologist, who pointed out that it was hard for Jesse to know what he was saying "no" to. She used the analogy of pizza – if you had never tried pizza, you wouldn't even know how much you love it.

At one point Jesse said to us that it didn't really feel like we were giving him a choice. We told him that if he strongly opposed it, he definitely did not have to get it. But if he was just put off by the idea of the surgery (which is really not that major, but does mean going under anaesthetic and wearing a very itchy head bandage for a couple of days), then we would rather he not make his decision based solely on that. We said we would push him in that direction because we thought it would be something that would be a benefit for him, but would never make him have the surgery against his will. In the end, he decided that he would get the second BAHA.

The surgery went well, and he was able to have it done in one stage rather than two this time, since he was older and the bone was thicker. While he was

healing, we learned that the new BP100 was being released, which is the latest version of the BAHA from Cochlear. There were some delays, so we had to wait awhile, but he finally got his hearing aid in November, five months after his surgery.

We encouraged Jesse to start a blog to document his experience, both with "going bilateral" and with the new BP100. You can read about his early impressions (<http://bahadude.wordpress.com/>) – he makes some interesting observations.

At this point Jesse has been wearing his two BAHAs for 7 weeks (his old BAHA compact on one side and the new BP100 on the other). Between school work and music, he is a busy kid, so I thought the best way to get his

input for this article was to interview him.

TK: "What do you think of having bilateral BAHAs so far? Do you notice much difference from when you just wear the one BAHA?"

JK: *I like having two BAHAs now. At first it was a little bit weird, and I had to get used to it, but it's normal now, and sometimes I don't notice that I even have the new one on. I find that most sounds seem louder now than when I only had one hearing aid. Sometimes this helps, but sometimes in places where there's a lot of background noise, it makes it harder to listen to the person speaking just because everything seems louder. I am getting used to it, though.*

One advantage I have found is when I am walking with my



friends. I don't have to position myself so that the side with my hearing aid is towards them anymore.

Also my mom says that I don't say "what" or "pardon" as much when I'm wearing both hearing aids.

TK: Did it take long to get used to wearing two hearing aids?

JK: *It took me about a month and a half to fully get used to it. At first I had to take breaks from the new hearing aid because it was really different and really weird sounding, sort of overwhelming. Gradually I started using it more and more (over a period of about 2 weeks), and then I started using it full time. Just about a week ago is when I noticed that it sounds normal now.*

TK: How do you find the sound quality of your new BP100 compared to the older Compact BAHA?

JK: *The BP100 is a lot clearer than the Compact. Another thing I noticed is when I use the background noise setting (directional microphone) on my new hearing aid, I find it a lot easier to hear in noisy situations.*

TK: You were hoping that having two hearing aids would help you when playing in the fiddle ensemble. How has that been?

JK: *I was hoping that having two hearing aids would help me hear other musicians when I am playing in my fiddle group. Unfortunately, there was something wrong with my BP100, and I got feedback whenever there was a loud noise, like my violin, so I couldn't wear it at rehearsal. We went back to the audiologist today and got a new*

one, but it doesn't seem to work any better than the first one. Hopefully they will eventually come out with new software and be able to fix it.

TK: Have you noticed any difference when you are talking on the phone?

JK: *Yes I have noticed one major difference; in noisy situations, it is way harder to hear because the background noise is twice as loud (coming through two hearing aids) but the person speaking on the other end of the phone is the same volume (only coming through one hearing aid). I have decided that from now on whenever I find myself in this situation I will turn off the hearing aid I'm not using for the phone.*

TK: Has your ability to localize sounds improved at all?

JK: *I can localize a little bit now – not easily, but I can a little bit. We've tried it a couple of times - I close my eyes and somebody talks to me and I try to localize the sound. Mostly I can find the general direction of the source of the sound, but I have troubles localizing behind me. My ability to localize sound has improved slightly since the first time we tried it – my audiologist recommended we practice localizing to see if I can improve my skills.*

TK: If you had to decide all over again knowing what you know now, would you decide to get bilateral BAHAs?

JK: *Yes. The only part that discouraged me in the beginning was the possibility that the surgery could go wrong and the knowledge that I would have to wear that really, really itchy head bandage. Since the bandage is*

“It took me about a month and a half to fully get used to it”

only temporary, and the risk of something going wrong isn't very high, I think the advantages outweigh the disadvantages.

TK: Do you have any advice for other BAHA users who are considering going bilateral?

JK: *Personally I think it's a good idea, even though the prospect of getting surgery may be daunting. It's a lot easier not having to always accommodate for only being able to hear on one side.*

Son Inspires Torchbearer

By Alfie Lau, Burnaby Now

Norman Wong won't forget his moment of glory in Maple Ridge on March 10. The North Burnaby man who works as a program supervisor for the Shaw Multicultural Channel won the right to carry the Paralympic torch by writing a 250-word essay on what the Paralympics mean to him. Wong's inspirational story revolved around his five-year-old son Colvin.

"When my son was born, he was profoundly deaf in both of his ears," said Wong. "Since his early years, he was your typical boy just having fun, and one wouldn't even suspect that something was not right.

"We started to have concerns when he didn't have verbal language when he reached the age of two. We brought this up at a doctor's visit, and then our doctor shared the same concerns and proceeded to move things along for hearing testing. After an audiology test, it was confirmed that he was diagnosed with severe to profound hearing loss."

Norman and his wife Patty were shocked and saddened by the news, but they immediately started looking into what Colvin's options were. Within months, Colvin was under the knife, and he had a cochlear implant, or digital processor, put inside his left ear. In addition, a hearing aid was put on Colvin's right ear.

Norman put in his application to run with the Paralympic torch in late-December and received a call in mid-January telling him he was successful.



Burnaby resident Norman Wong was inspired by his son's hearing loss to run with the torch for the Paralympic Games on March 10. Wong was selected to carry the torch after writing an essay on what it meant for him.

"I was ecstatic when they called," said Wong. "I just thought this was a great fit for me, and I'm so honoured to be able to run with the Paralympic torch."

Norman isn't sure that Colvin and his younger brother Kade, 3, realize the significance of dad running with the torch, but they will once they see the \$400 investment Norman is putting into the relay.

"Yes, I'm buying my torch, and I'm not sure what I'm going to do with it, but when the kids ask, I can tell them why it's in the house," said Norman.

Norman has tickets for the opening ceremonies of the Paralympics, and he hopes to attend some sledge hockey games as well. Because Norman works downtown, he had a close-up view of the Olympic cauldron.

"It was amazing to see how the city came alive during the Olympics," said Norman. "I had the opportunity to see some women's hockey and some speedskating, and there was just a great energy there."

Wong hopes that energy translates to the Paralympics that run until March 21.

"I think people will really embrace the Paralympics because there are so many stories about the athletes' courage and inspiration.

"I think that all the athletes are amazing people as human beings. It's this type of positive human spirit in overcoming physical adversity that I want to share this with my son someday.

"Just because one may be different in some way shape or form, greatness is still possible if one puts in the passion and hard work. This is evident with all the Paralympians of 2010."

Reprinted with permission from Burnaby Now, March 13, 2010

Photo courtesy of Troy Landreville/ The Times

Signing Course First in North America

By Jennifer Moreau, Burnaby Now

The Burnaby school district launched North America's first online American Sign Language course last month.

"It's about access, it's about bridging cultures, all cultures of the world," said Karen Taylor, the administrator for the Provincial Outreach Program for the Deaf and Hard of Hearing. The comments came as Taylor was speaking and signing to the trustees and district staff at the Feb. 23 school board meeting.

The new course means deaf and hard-of-hearing students can get equal access to a language their hearing counterparts can, Taylor said. "I believe it's going to be a wonderful success, not only for the district but also for the province," she said.

Any B.C. student can take the course and get credits for a second language. Adults and international students can also sign up. The course could be useful for anyone who needs to learn American Sign Language, including special-education assistants or bank employees, for example. American Sign Language is the third most



Sign of the times: Instructor Jo-Anne Robinson signs to six-year-old Michael Maughan, who's with his special education assistant, Bonnie MacRae, on the monitor. Robinson is teaching the Burnaby school district's online American Sign Language course. Larry Wright/BURNABY NOW

commonly used language in North America.

There are instructor videos, entirely in American Sign Language, that teach students signing and finger spelling. There are also live video chats so students can get help from an instructor or practice with each other on split screens. The course instructor, Jo-Anne Robinson, connects and signs with students around the province via webcam, Skype or IChat.

"Nobody else is doing that," Taylor said. "It's cutting edge."

Students can go at their own pace, but the course must be completed in 10 months.

The course is free, but there is a \$100 deposit for materials. International students pay \$730 for the course.

Thanks to the Family Network for Deaf Children for forwarding the information of the online ASL courses to us. Details about these courses from BC Provincial Outreach Program for Deaf and Hard of hearing Students is also posted at <http://www.fndc.ca>.

Reprinted with permission from Burnaby Now, March 17, 2010

To register, please go to Burnaby Online Website:

<http://online.sd41.bc.ca>

Click on 'Courses', look under 'Modern Languages', then click on 'Intro ASL 11' to read the course descriptions for info about how a student is assessed throughout the course as well as prerequisites

When a student is ready to register, click on 'Register Now'

The “Daily Draw”

A message from the Drawing Network:

- Bob Steele, for the Drawing Network, Associate Professor (Emeritus UBC)

From the age of two, children use spontaneous drawing as a language medium but the potential becomes real only if adult care-givers take an interest by motivating themes. We believe that most children are still innocently deprived of drawing as a daily or frequent experience in their growing up.

Spontaneous drawing contributes to 1) mental growth 2) intellectual development 3) emotional health 4) enhanced learning 5) literacy 6) parent/child bonding. It does not require teaching, only motivation. *You don't have to be a teacher or an artist to motivate children to draw!* A language emerges and develops through practice.

The Drawing Network distributes pamphlets to help parents establish a “daily draw” routine and teachers to integrate drawing into the school curriculum as an auxiliary language, kindergarten through middle and secondary school. There is no charge for pamphlets but small donations for printing and mailing are welcome.

Visit our website at <http://drawnet.duetsoftware.net/>

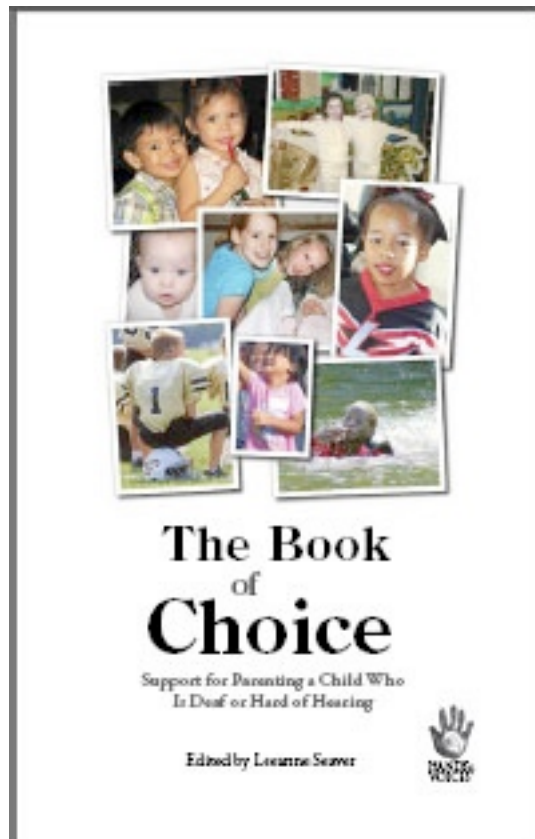


The Book of Choice

Christine Yoshinaga-Itano, PhD

The Book of Choice is a wonderful expression of what we know to be true: parents sharing directly with other parents of children who are deaf or hard of hearing bring an essential kind of hope, inspiration and empowerment. This book is an amazing resource that captures that unique quality, and opens our minds to broader, more holistic views of parenting a child with hearing loss. It's just the kind of thing you'd expect from Hands & Voices.

To order your copy, please go to: <http://www.handsandvoices.org/resources/products.htm>



Thank You!

We would like to thank the following organizations and individuals for their generous donations.

BC Children's Hospital Family Support Groups/Networks Funding Committee
 Bobbi Best
 Teresa Kazemir
 Tracy Ma

Thanks to our hard-working and dedicated board members and volunteers, we have organized several successful events for families (e.g. picnic, family social and parent workshop), launched the BC Hands & Voices website, published 3 newsletters, all in less than 2 years!

Let us know how we could support you. Drop us a line at info@bchandsandvoices.com

Of course, we would like to have your help too. Send us a story, questions, news, your thoughts. Or donation!

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.



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Contact us via email:

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Visit our website:

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