

Courage & Resilience

Humans of Hear

HEAR FOR THE HOLIDAYS EDITION



After graduating from Cegep, Vanessa Séfriu earned scholarships to pursue her higher education in the United States while representing her schools on the soccer field. After completing her Bachelor's and Master's degrees in business administration/marketing concentration, she spent one year in England where she helped a visually impaired lawyer. She then came back to her hometown because of Covid and pursued her interest for corporate social responsibility by joining Hear Entendre Québec under the Canada Summer Jobs program.



Coming to Canada

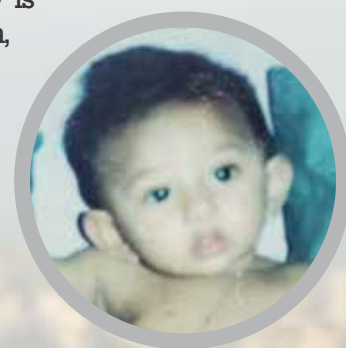
"Never judge a book by its cover" is an expression we often use to remind ourselves that everyone has a different story and to be mindful of those differences when interacting with each other. You never truly understand someone until you take the time to listen to their story with an open heart and an open mind. When you truly pay attention to the storyteller, you get to relive their experiences and their emotions with them. You become them for a brief moment. Today, you'll have the chance to place yourself in the shoes of a very courageous and resilient individual. Are you ready to explore the bottom of this person's iceberg? I think you are!

My parents never really suspected anything particular about me until one day when they found me sleeping in a really noisy environment. They found it odd so they took me to the doctor and that is when my journey began. I was 8 months old when my parents were informed for the first time that I was more than likely born deaf/hard of hearing. Doctors would normally find such a defect earlier in a baby's life based on a variety of specific cues, but since I was an overall healthy baby, my parents never felt the need to take me to the doctor before that day. It is thought that my deafness may have been caused by my mother contracting German measles when she was pregnant with me. This would have then led to my bilateral congenital rubella syndrome (CRS).

Apart from the fact that all I could hear/sense without any hearing support devices were vibrations, I was overall a typical child. I had parents that loved me enormously and spoiled me

just enough. My sister, who was three years younger than me, and I got along very well (if you do not count the times she stole my new toys...). My parents always told me that I was a really happy and playful kid. I apparently loved to talk. I only spoke my native language at the time. There is an expression in English to describe someone like me... a chatterbox! I also had a big heart and I always wanted to help others. I would continually show generosity towards those that seemed in a more difficult financial situation than me. So overall, I was privileged to have never lacked anything in my childhood. What else could I have asked for? Well, maybe there was one thing... my hearing.

You have to understand that I come from the small country of Bangladesh, which is nestled between India and Myanmar (Burma). When I was a child, resources for the hard of hearing community were scarce even in the big cities. I was lucky to live in the highly populated capital, Dhaka, so I did have some resources available to me, but they were limited and not really advanced technologically. My mom knew that she had a big decision to make, and like any mom, she made it in the best interest of her child. So at 5 years old, my mom announced to me that we were moving to Canada! Canada...this cold yet cool place where it snows all year long, where you get to interact with polar bears, and build your own igloo...at least that's what I thought. Let's say that where I come from, snow is as rare as sugar pies. Ya, right, it does not exist. It is way too hot for that.



Pathway to Accessibility

When I first arrived in Montreal, I had to split my time between two schools: a public school and the Montreal Oral School for the Deaf (MOSD). The MOSD helped me improve my listening and speaking skills while the public school taught me the usual subjects we all learn at that age. At the MOSD, I was soon retested by an audiologist and diagnosed as completely deaf in my right ear and deaf at around 98% in my left ear. Due to my results, I was fitted with two hearing aids. The principal at the MOSD, Martha Perusse, told my family and I that I had a huge task ahead of me. I had to learn English – remember, I only spoke Bengali when arriving in Canada – and adapt to my hearing loss. This is when I started to attend MOSD classes full-time.

My parents made sure I put in the work quite quickly. My mom was determined to make me learn this second language as fast as possible. “I spent hours daily after work going through the alphabet with my [little sweetheart], just trying to make sure [my dear] could pronounce the letters accurately,” she explained in her testimonial. “We [speaking of her husband and herself] also made sure to speak English in the household, rather than our native language, to ensure [the apple of our eyes] could be surrounded by English,” she pursued. I truly have to award some of my life achievements to her and her dedication. I would not be where I am today without her.

Unfortunately, even if my parents had wanted to do something more before coming to Canada, it would not have been possible. In Bangladesh, resources and

technology in this particular medical field are scarce. Bangladeshis’ access to support for hearing loss, whether diagnosed at birth or acquired later in life, is not anywhere close to Canadians’. It should not be this way but it is a reality.

This lack of resources for people with hearing loss in Bangladesh was definitely one of the main reasons why my parents decided to move. My mom wanted to make sure that I would have a better life. “I wanted my child to be the best [they] could be, despite the fact that [my little pumpkin] was hearing-impaired, and I knew that we needed to move to a country that would support us in providing the best treatment for my [babu].” I will always be thankful to them for leaving behind everything they had to move across the globe for me.

In all honesty, I did have a sort of antique hearing aid machine back in Bangladesh. It was quite big... Okay no, it was enormous! It was this huge rectangular box attached to straps and I had to carry it around my neck everywhere I would go. Imagine your kid carrying his lunch box around his neck at all times. Well that was me. Not really practical when you are trying to play around, let me tell you!

"We changed the words inside of the brackets to preserve the anonymity of our surprise person until the big reveal!"



Where was I... Oh ya! So as I was saying earlier I got tested by an audiologist at the MOSD and was referred to get two new hearing aids. I was six years old at the time... Quite late, hey, I know! In fact, the first five years of any human being are critical to their development. Throwing some hard facts at you! Considering that I spent the first eight months of my life without my parents even knowing that I was basically deaf, and the next four years with limited help from an antique hearing machine, I most likely missed out on a lot. In all honesty, even the hearing aids I was provided with at six years old were not the greatest solution for me. It is not until I got a cochlear implant (CI) a couple of years later that I truly saw considerable improvements with my hearing capabilities.

I was ten years old when I was approved to get a cochlear implant for my right ear. A CI is surgically implanted behind the ear and directly stimulates the auditory nerve. For someone who has profound hearing loss like me, it is quite the right option. Once you recover from the surgery, it only leaves a small scar behind the ear. Nothing too complicated to understand in perspective, but at ten years old, it was a completely different story. At the time I did not understand the whole concept and I was very scared. Just the word "surgery" gave me chills. Nevertheless, my parents decided that it was what was best for me, so my dad and I drove to Quebec City and spent a total of two weeks there. My mom, on her end, stayed home as she continued working and looking after my sister while we were gone. Although I am grateful that my Dad was there, I missed the support and love from my close family and friends. Those two weeks were quite lonely.



When I returned to school, after my long recovery and rehabilitation, I was like the new kid on the block! It is not every day that a ten year old student becomes the hot topic of school. Everyone was asking me questions about my new equipment which made me feel important and smart. I even made a few of my classmates jealous. I have to admit that I was quite apprehensive about this new technological device at first, but once I started hearing better, I was quite hopeful for my future with all the improvements that the CI offered. I felt like nothing could stop me now, but then, like it is the case for most kids, high school hit me.

In high school, I started having difficulty following in class, even with the help of my CI I learned that the added technology for my hearing was not the only thing I needed to rely on in order to communicate and understand properly. I needed to use speechreading and other communication strategies. Moreover, as my high school educators were less sensitized to my communication needs, they did not always



adapt their teaching style. Most of them spoke too fast and turned away while talking to me. Even if I made them wear my FM device, I could not follow them well. An FM device is a wireless assistive listening device that transmits sound from the person speaking to the listeners. This helps people with hearing loss, like me, to better hear a speaker from a distance and is especially useful in a noisy environment like a high school classroom! Oh, and that's the other thing! I had to carry my FM device from one class to the next because high school is not like in primary school. You have a different teacher for each subject rather than one for all of them. This added to my challenges. I had to adapt to each classroom's environment and each teacher's tone of voice. Not only that, but I was also the only one in my classes that had a hearing loss so I felt quite different.

This had an affect on my social life. Making friends and dating was not my cup of tea. I was quite shy and the fact that I had hearing loss did not help. It got quite lonely at times. Things eventually started getting better. I began to get support from a note taker and an oral interpreter* which helped me enormously in the classroom. I also joined the school's basketball team in Secondary 3, which is a sport I really enjoyed playing. The coach was really accommodating and made sure to speak slower for me and get my attention before

speaking. I did not get to play in a lot of games due to my disability, which was disappointing, but when I did, I felt like a basketball superstar. I also grew to love participating in my drama classes as they allowed me to express emotions and act certain scenes without using too many words. I truly felt like I was part of the group during that class. By the end of my high school years I felt I belonged.

In 2010, I proudly graduated high school. Although I found my way, I was happy to have my tough high school journey behind me.

*Note taker: A note taker summarizes lectures in written (word) form.

*Oral interpreter: An oral interpreter helps to deliver a spoken message from someone who speaks to someone who is hard of hearing. The oral interpreter will repeat the message at a slower speed, use fewer words and clearly enunciate each word.



Thriving

If you remember well, I had an interest in dramatic arts in high school. I pursued this creative interest in August 2010, a couple of months after proudly graduating high school, when I decided to join a training school. So in order to attend the program, I first had to go to summer school to pass my high school maths. My perseverance paid off and I ended up receiving my diploma.

To tell you the truth, a big reason why I chose the program I chose is that my parents agreed to it. They are really strict parents, so I had to make sure that they would approve of my career decision. But the main reason for my choice was the creative liberty and the artsy side it would bring me (hint hint)... I would have a way to express myself in another form than speech. I would still be able to put my signature touch out in this world.

This time, I made sure to get support from an interpreter/notetaker right from the start. I was able to get a bursary from the government to pay for training school, but my parents had to pay for the support worker. My parents have always been my biggest advocates and did everything in their power to see me succeed and achieve all the goals I may have set for myself. Thanks to their help, I completed one year and a half of the program, and self-taught myself the printing aspect of the program through my personal work experiences.

My first job had absolutely nothing to do with what I studied, but it did lead me there eventually. I'll get there

later. So I got my first real job thanks to my parents. They were working in a clothing warehouse and were able to get me in. My first role in the organization was to place stickers on clothes. I worked along with my mom in that department for around two years, and then was moved to the packaging department, where I worked along with my dad for around a year. Most, if not all, of my coworkers were pretty advanced in age, so I did not really have anyone I could become friends with there but at least I had my parents to keep me company. It was also nice to have my parents there to explain to me the different instructions and how the machines worked. My supervisor was also quite friendly, which helped a lot, but working in the factory was overall hard for me because it was a really noisy environment. Thankfully, I was able to get a promotion to work in the offices after working on the floor for around three years.

The promotion did not initially come with a better salary, which is something I should have definitely asked for when thinking back about it. Generally speaking, people with disabilities have higher unemployment rates and earn lower incomes than their counterparts with no disability. I eventually asked my supervisor for a raise and got it, but I would be curious to know if this raise would have been granted automatically to someone who did not have a disability if they had been in the same position. Nevertheless, this work opportunity definitely allowed me to gain insightful experience in relation to the program I had studied in previously.



My supervisor was getting a little overwhelmed with work, so he put in a good word about me to the human resources team, knowing my educational background. Sooner than later, I was now the one participating in the design of the clothes' stickers and other embroideries that I used to simply stick onto the products (hint hint). Some of my other responsibilities were to create color coding for clothes and talk with clients about what they wanted for their prints, among others. I have to admit though that it was sometimes hard to understand clients, so I started getting help from a support worker that would be present during those interactions to make sure I understood the instructions correctly. I probably had that position for around two years until I was laid off after the company merged with another one. Nevertheless, it was indeed an amazing learning experience.

It took me some time to find a new job afterwards because I did not speak French. In high school I took some French classes, but I only learned the basics. As a hard of hearing individual, I was allowed to take limited classes. It was nice at the time, but I did feel its effects later in life. Not speaking French really restricted my ability to get hired. Most employers prefer someone who is at least bilingual, and English speaking organizations are very limited. Maybe one day someone will create French courses that will be designed specifically for the anglophone hard of hearing community. We should all be given the tools to succeed.



So, after searching for quite a while and being unsuccessful, I decided to spend some time volunteering in a company that allowed me to work on small visual projects. I really enjoyed it since I was able to use the set of skills that I had learned throughout training school. My supervisor started noticing the quality of my work and slowly but surely, I developed a working relationship with them. I was soon hired on a contractual basis and then under a special Québec grant as a full-time employee. I slowly gained more and more responsibilities and was involved in more and more projects. I really liked working there as I felt valued.

The working environment also helped me to thrive as my bosses made accessibility a priority. Employees were trained on the subject and everyone made an active effort to put me at ease. It was a learning process overall, but it was successful. I learned to work with them and they learned to work with me, and slowly but surely we developed communication tools and styles





that fit my hearing needs. For example, my coworkers adapted their approach and their speech during meetings or when talking to me directly. It made it much easier for me to understand what was expected of me daily. The open environment also made it more inviting for me to participate in discussions. I was always encouraged to share my ideas and opinions with the rest of the team. I know that when I did share them, they were not going unheard. It helped me feel like an equal and respected member of my team. Joining the organization also allowed me to become much more independent at work as my parents were no longer just around the corner. I had to learn to speak up for myself during meetings, which was not always easy at first, but it did improve over time with practice. I truly gained a lot of confidence since I started working for this company. I am reminded often by my coworkers and supervisor about how much growth they have seen in me throughout my whole journey with them.

In the meantime, I also became a member of Communicaid for Hearing Impaired Persons (CHIP), now Hear Québec, an organization that improves the wellbeing of those affected by hearing loss and helps prevent hearing loss in future generations. It is following my attendance at a youth focus group with CHIP that I decided to join the not-for-profit. It was an old friend of mine from MOSD, Haruniya, that had reached out to me during the winter of 2016 to invite me there. I really liked the event, and felt a sense of belonging as I got to meet other hard of hearing individuals like me. Joining their community was there-

fore pretty natural to me. I started participating in many of the organization's events and activities. The first big event I was selected to attend in the name of the organization was the 2018 CHHA Youth Forum that was hosted in Ottawa (hint hint). I attended it with Ashley Mayoff, who was a Noise-Induced Hearing Loss Program animator for Hear Québec at the time.

I used to dread those kinds of events. They made me really nervous. I am not the chatty kid I used to be. I am quite shy and I do not talk as much, especially in new environments, unless it is with people I know well. But, to my surprise, I really enjoyed the Youth Forum. I got to meet even more people that had a disability like mine, hear their stories, learn a little more about accessibility, and much more. To be honest, I now look forward to those kinds of events, awaiting the day I will be able to see some of the people that I met there and that I can now call my friends. I did have a close group of friends prior to joining Hear Québec events and activities, but I have extended it considerably ever since.

Moreover, something that Hear Québec does well is to take into consideration the needs of the hard of hearing community when planning and advising events and activities for us, which allows me to enjoy every facet of them to their full potential. For example, the organizers of the 2019 Canadian Hard of Hearing Association (CHHA) National Conference and Trade Show hosted in Montréal made sure to have an interpreter present for us, live captioning, and sound amplification.

It was at the 2019 CHHA Conference that I learned about a new hearing aid technology that would encourage me to get a hearing aid. Advanced Bionics, one of the companies that had a stand there during the event, was promoting their new Naída bimodal hearing solution. I quickly read through their pamphlets and decided to investigate the option. To give you a brief overview of the technology in question, their hearing aid would somehow be able to communicate directly with your cochlear implant, or vice versa, so that you continue to get the clarity that the CI provides while getting the depth in sounds and loudness that the hearing aid allows. Sound signals are somehow sent in both ears and you also get a bunch of cool features, such as focusing on a speaker even though they are not facing you, hearing in both ears during a phone call, and toning down unexpected loud noises. It's apparently super comfy and easy to use.

So after understanding hearing balance a little better and being encouraged by people at Hear Québec to self-advocate more, I decided that it was time for me to make an appointment with Mackay (now Lethbridge-Layton-Mackay Rehabilitation Centre) and investigate a little more about what could be done for me. The audiologist I met with took care of everything and soon after I was receiving an email from Gabrielle Masliah, from Les Centres Masliah, who had successfully found an hearing aid available for me in Laval, the city where I live at the moment. Et voilà! I truly recommend people that are profoundly hard of hearing to discuss the option to use both a hearing aid and a cochlear implant with their audiologist. For me, it was a game changer.

The 2019 CHHA Conference was also memorable for me because I received an award from Hear Québec during the event (hint hint). Whoop Whoop! I truly felt empowered by the gesture and will forever be grateful to this organization for supporting me.

So trust me when I tell you that your disability doesn't define you; it's only part of you. You can truly achieve whatever you put your mind to.



Covid - Starting Over

I was very proud of my achievements with my career – I truly felt like I was thriving. I was also achieving lots of things outside of work. For example, my social life was better than it ever was. I found a group of friends that love and understand me. We saw each other quite often to play video games and basketball together. We even went on summer trips together to a chalet! Life was great. Then... COVID struck...

When COVID hit all of us at the beginning of the year, it took an enormous toll on me. Like most people, the plans I had with my friends and family members were shattered. All the events I was looking forward to were cancelled, including another Youth Conference that CHHA was going to have in the summer. I soon felt isolated from the world all over again .

Working from home was almost impossible for me. I could not follow what was going on during virtual meetings because everyone would speak at the same time, and there was no live captioning so I could not follow along. Just doing something as simple as asking for the location of an item at the grocery store was so complicated. I had to find a picture of the item on my phone and show it to the grocery workers for them to understand what I was asking for. The confidence that I had gained over the last few years faded.

This whole pandemic is a nightmare that people who are hard of hearing have never woken up from. It is also really hard for me to get government information and resources about COVID as the Government did not make it accessible for the hard of hearing community. For example, there was not – and is still not – a way to book an appointment for a COVID test other than by speaking to someone on the phone. I therefore have to ask a family member to book an appointment for me. Goodbye, independence.

Oh, and let me tell you about a fun COVID story that happened to me (I'm being sarcastic here). It's about the first time I got tested. My experience was horrible and I am not even being dramatic. So let me put you in context. First, the environment was super noisy. It was like in a big arena. They even had fans on to make sure that there was constant airflow. We also had to keep a social distance of 2 meters between each other, even with the workers that were there to help us. Add to this a mask and face shield, and you have the perfect com-

bination to make the life of any hard of hearing individual a nightmare. It was already a challenge for people that could hear perfectly to understand the workers there, so can you imagine my experience... HORRIBLE. So let me tell you that if I had been asked to rate this testing center on accessibility, they would have scored a big fat 0/10. The worker that was responsible for taking my information at the entrance did not even want to write down her questions when I asked her politely. Very upsetting!

Thankfully, improvements were made in most sectors. At work, we started using Google Meet over other alternatives as it permitted free captioning during meetings. Some organizations, such as Hear Québec, started distributing clear masks and face shields, which allow people that wear them to read each other's lips and see each other's facial expressions while staying protected. Most people learned to speak clearer while they had a mask on. My second testing experience was much better. It was at a different location, but the person I needed to communicate my information with was much more helpful. We used his computer screen to communicate with each other.

Overall, I am happy to see that more efforts are made to make things more accessible for us. However, it is irritating that I had to wait so long to gain the same accessibility as some of you. I am still hitting a lot of barriers but I am adapting just like I had to do for so many years.



Part 5 of 5

Reveal the whole article with pictures





Dear reader

We hope that you enjoyed the story of one of our members. This is the final part of our five part series that was released throughout the month of December 2020. Our goal was to show the impacts of someone living and adapting to hearing loss, and how Hear Québec can support our members through this process.

We hope that you followed, liked, and subscribed to our social media pages to keep up with the rest of our Calendar of Hope. If not, you can still go back and see what we have posted throughout the whole month! The story is also featured on our blog, so you can now reread all parts all in one place! With your donation we can continue to provide reliable and enhanced services, and support to those affected by hearing loss all year long. Together we stand for accessibility... Together we can! [Click here](#) to donate!