



# **INTERVIEWS WITH 23 ADULT COCHLEAR IMPLANT USERS FROM 9 COUNTRIES**

*CI Project: Collecting Cochlear Implant User Stories*



Le Peng Tee

## **Credits**

**Stories contributed by:**

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# About the Interviewer



I am Peng (my full name is Le Peng, Tee) and am a cochlear implant user. I was born deaf in both ears and got implanted with CI when I was 2.5 years old in 1997. From being a kid to a teenager and now a young adult, I have experienced struggles and triumphs – mostly social ones.

I attended mainstream schools throughout. I have achieved a fair part of what a successful CI user should look like. I was elected the role model of the year in primary school and secondary school. I attended Hong Kong University of Science & Technology with an entrance scholarship and later State University of New York at Plattsburgh, where I graduated with the highest distinction in B.A. Sociology. I am now working as a Marketing Executive for a Singapore-based digital marketing agency.

Though I realize that external recognition does not automatically translate into self-acceptance. I realize that **no matter how advanced the Cochlear Implant (CI) technology has become, it is not going to make a significant change if CI users do not feel accepted for who we are.** I believe many could relate to me.

We cochlear implant users need to acknowledge and understand our own struggles before the people around us can effectively support us.

Through CI Project, I reach out to fellow cochlear implant users to chronicle their experiences and seek to understand the perspective of the people close to us. The goal is to empower CI users to live out who we are – that takes more than just technology. Here are the cochlear implant user stories.

You may check out this [two-minute video](#) about my CI journey produced by Cochlear Southeast Asia.

I also share perspectives and realizations that have shifted the way I see and experience things on my [personal blog](#).

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# *The travel host that inspires*



*Alana wants to be the role model that she had hoped to have as a kid.*

Self-esteem is a mysterious puzzle to many Cochlear Implant recipients, especially for teenage recipients and adults who get implanted for the first time. They tend to be acutely aware of the presence of the magnetic device on their head. They often grapple with the feeling that the CI speech processor does not look good on their heads. Cochlear implant user **Alana** is not shy to make her speech processor visible, even when under public scrutiny.

### **Alana is an award-winning travel host**

Alana is a co-producer and the host of Follow Alana ([YouTube channel](#), [Facebook page](#)), a travel show about her visits to places and people across the globe. The award-winning international show is aired in several regions in Asia (including Taiwan, Singapore, and

China). In an interview over a video call, Alana shared that her mother's guidance was instrumental in building up her self-esteem as a CI recipient.

### **She is a unilateral CI user**

Born to a Taiwanese father and an American mother, she has been profoundly deaf in both ears since birth due to a rare form of deafness that resulted in a malformation of both cochleas. She underwent experimental surgery to have CI implanted in her left ear when she was almost 3 years old. She was later implanted in her right ear at the age of 15. Unfortunately, it was too late for language acquisition in the right ear. Therefore, she depends solely on her left ear for communications despite having been implanted in both ears.



**“There is no such thing as  
the kid being too young  
to know about this.”**

*- Joanna Nichols, Alana's mother*

### **She runs a foundation dedicated to the HOH community in Taiwan**

Alana worked in the international business field in Asia, Australia and Europe prior to her current travel host career. On the side, she has been helping out with the Children's Hearing Foundation (CHF) which was founded by her mother, Joanna Nichols. She has been involved with public speaking and video production for the foundation. A producer spotted her flair for the stage and offered her an opportunity to host a travel show. That opportunity later led to the inception of Follow Alana.

### **Her mother was a great source of support**

The positivity, encouragement and love from her parents since a young age established a solid foundation for her future. Such foundation has empowered Alana to develop her own identity and advocate for herself. Alana recalled her mother telling her on the very first day

of school that she needed to educate her classmates and teachers about hearing loss and her needs since not everyone would have had such awareness.

Alana's mother would make her practice the line -

*“Hi, I am Alana. I have hearing loss so I may not hear you properly and I need you to face me when you're speaking to me.”*

Being upfront about her hearing loss gave her more confidence. When people discriminate, she would have had the self-confidence to stand up for herself. Today, Alana repeats the same line opening - but to a global audience who follows her travel show.

# *The epitome of CI parents' hope*



Cochlear implant user **Alexandra (Alex) Bushby**, a 25-year-old Canadian, is currently a PhD candidate in Biostatistics at the University of Toronto.

She enjoys watching TV, playing computer games, baking and hanging out with friends during her free time. She's been involved in gymnastics as part of her extracurricular activities at school.

This short profile of **Alex** sums up the ‘normal’ life - the autonomy to live as one wishes without being deprived of dignity and economic independence - that many cochlear implant (CI) parents hope for their kids.

I interviewed Alex over a Zoom call to find out what might be the key to the CI parents’ hope. I learned that her family, especially her mother, played an instrumental role in grooming Alex to be the young woman she is today.

Her diagnosis of profound hearing loss came in soon after she turned 3. She was implanted in her right ear the same year. She was later implanted in her left ear at age 14 as part of a clinical study.

Alex described her experience growing up as being fairly decent. It helped that her mother was an occupational therapist. Her mother had to proactively find ways to support people with needs and to help them succeed as part of the occupation.

This helped set the tone of the family’s interactions around Alex’s cochlear implant when she was younger. Her family members were open about her CI. The people around were made comfortable to ask questions about it. Today, Alex wants all CI users to know that we shouldn’t be ashamed of our implants.

She lets up her hair to make her white CI speech processors visible. This helps others to have a sense of her hearing condition. She tries to sit next to someone who will help convey the conversations in a large-group setting. Whenever possible, she seeks one-to-one conversations. Like her occupational therapist mother, Alex has learnt to proactively find workarounds in her daily situations.

At school, she requested and received assistive services like the frequency modulation (FM) system, captioning and note-taking. She also tended to sit closer to the front of the class.



*Alex (second from left) and family*

So that she could hear her teachers or lecturers better. At the universities, she would make sure to connect with the Accessibility Office at the beginning of each term.

Alex aspires to work with data sets - either as a Biostatistician or a Data Scientist - as her career. She also looks forward to knowing and meeting more deaf and hard of hearing young adults. And be of support. “It makes me sad that some among us don’t feel as ‘successful’ with our CI experience as seen in the CI Project survey ([CI User Experience survey](#)),” Alex said.

*Interviewer’s (Peng) note:*

*Alex’s family and the culture she lives in have been especially influential in*

*shaping her healthy outlook and social experience.*

*The real problem around hearing loss is how we (CI users and the people around us) see it, not the condition itself. While there could be complications or physical discomfort with using CI that impede one’s daily function, the majority of the constant worries around hearing loss are psychological. They often are related to being comfortable in our own skin (self-esteem), being accepted by people that matter to us (dignity & social experience) and being perceived as competent (economic independence).*

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# *Ashlei marries self-advocacy with*



# *entrepreneurship*



*Ashlei attending speech therapy as a kid*

Many of us have gone through a period, especially in our teenage years, when we wanted to conceal our cochlear implants. But we would also go through a period when we want or need to make our hearing needs be known to others. Cochlear implant user **Ashei Powell**, one of the first youngest CI users in the world who got implanted in 1990, and started [Deaf Wearables](#) to help people who have experienced the same. Ashlei shared her story with CI Project via email correspondence.

### **Ashlei was one of the first kids to be implanted**

A mother of two boys, Ashlei became deaf from meningitis when she was 11 months old. She first received her implant on her second birthday in 1990 when the US FDA (Food & Drug Administration) just approved the use of CIs on 2-year-

olds. She received her second implant in 2005. Ashlei's parents have been very supportive in her hearing journey since the beginning. Many around them frowned upon their decision of letting Ashlei undergo CI surgery when it was still a novelty for children use and perceived as a substantial risk. They blazed their way through - from getting help with Ashlei's learning and speech to raising awareness of Ashlei's deafness. Ashlei's mother created wearables that would help those around Ashlei be aware of Ashlei's deafness when Ashlei was younger. For instance, she would make Ashei wear a reflective vest with the word "DEAF" imprinted on it with a Sharpie pen on skiing trips. It was awkward for Ashlei despite the good intention behind it.

**“This world has a lot of people that may think both good and bad things about cochlear implants, but don’t let it keep you from wanting to hear again and enjoy hearing amazing things in life again.”**

### **She experienced first-hand the need for wearables**

In summer 2017, Ashlei joined a Tough Mudder competition, which involves a 10–12-mile-long muddy obstacle courses, with her husband. She had to take off her speech processors or they would fall off or get lost in the mud. She needed a way to let others understand that she was not going to respond if they yell at her because of her deafness. She could not find anything online that she could either put on her clothes or a temporary tattoo that would serve as a visual cue. She turned her frustration into actions. She started producing wearables: headbands, shirts, temporary tattoos, seat belt covers, etc. Today, she makes these fashionable and potentially life-saving items available for purchase online. You could visit [Deaf Wearables](#) to learn more.

### **Learning to advocating for herself**

Ashlei has learned to advocate for herself along the journey. She used to

dislike joining group meetings because she sometimes struggles to be involved in the group conversation, especially in a confined setting like a dining table. She has now learned to speak up and let others know about her hearing needs. Ashlei has also learned to cope in situations where people belittle the value of her work because they are clouded by their prejudice towards deaf individuals.

*“This world has a lot of people that may think both good and bad things about cochlear implants, but don’t let it keep you from wanting to hear again and enjoy hearing amazing things in life again,”* Ashlei said. *“I can’t imagine not hearing again and not using this incredible gift of hearing again.”*

When not at work or working on Deaf Wearables, she spends time with her two boys (one of them born in October 2019) and her husband.





*Ashlei with her husband and their two boys*



*Display of Deaf Wearables products*

*Bringing  
together a  
HOH/deaf  
community*



Cochlear implant user **Bowen Tang** spends time with hard of hearing (HoH) and deaf young people both at and off work. Turning 30 this year, Bowen's day job is a Teacher for the Deaf and Hard of Hearing at Children's Hearing & Speech Centre of British Columbia, Canada. He is also a co-founder of the [Canadian Hard of Hearing Association](#) BC Youth Peer Support Program and the President of [International Federation of Hard of Hearing Young People](#) (IFHOHYP). He experienced both sides of privilege (and the lack thereof) growing up.

Today, he believes the privileges he has received should not be extras but something that is available to all.

### **Born in HK, moved to Canada**

Bowen was born in Hong Kong in 1990. He was first identified with moderate hearing loss at age 2. He first wore hearing aids, which helped him hear sufficiently well then. He moved on to a mainstream primary school. Despite his decent progress, Bowen's parents felt that the environment in Hong

Kong then lacked the conditions and resources needed to help him flourish. They migrated to Vancouver, Canada in 1998.

### **Bowen lost all his residual hearing one morning**

One morning in 2000, he woke up with no hearing at all. Hearing aids were no longer of help. He was later diagnosed with large vestibular aqueduct (LVA) syndrome, which eliminated his residual hearing. At age 10 in 2001, he got implanted on his left ear. It took him another three years to re-learn listening with a cochlear implant (CI). He has been relying on his left ear to do the listening work for both ears since then until re-wearing a hearing aid (HA) on the right ear in 2012, becoming bimodal (HA+CI). He received various kinds of support to help him navigate the challenges related to his hearing loss.

### **He received comprehensive assistance**

The Canadian health care system covers all his hearing equipment maintenance and upgrade costs. He received assistance from a teacher who specializes in helping school kids with hearing loss assigned by the government. He met the teacher one-to-one three times a week, 40 minutes each time, to ensure he was all caught up with his classes. He also had access to hearing assistive technology, like Roger pen, and services,

like in-class captioning at university. Roger pen is a kind of FM (frequency modulation) device that helps one to focus on listening to the speaker by pointing the Roger pen to the speaker. It is like how the mic works, except that it streams the sound straight to your hearing device instead of magnifying it for everyone in the room.



### **HOH community is a pillar to his life**

One more crucial source of support Bowen has received is a hard of hearing community. He might be the only kid with hearing loss in his classes. But meeting with other individuals with hearing loss of different age groups outside school has helped ward off feelings of isolation common to kids with hearing loss. This is what Bowen felt was missing in the larger society and is now dedicating his time to bring together individuals with hearing loss.



*Bowen with fellow IFHOHYP board members*

He co-founded the CHHA-BC Youth Peer Support Program in 2012 and is currently the president of IFHOHYP. These two groups organize events to bring individuals with hearing loss together on a regular basis. CHHA is based in Canada while IFHOHYP was first founded in Europe and is now

seeking to expand to other regions. Bowen is now driving the IFHOHYP expansion to Africa, Asia, and South America. “They all boil down to one thing - bringing together a community,” Bowen said of what drives his active involvement with CHHA and IFHOHYP.

# *David opens up on* **BEING SOCIAL**

To have a solid social footing to express who we are apart from being a Cochlear Implant recipient is one of the biggest obstacles we face. It is not the lack of competence that is hindering us. Cochlear implant user **David Romanowski** did well throughout his school years but only began to fully enjoy his social life after leaving school.



## **Growing up with CI was a pain for David**

David was born profoundly deaf in both ears. He was implanted in his left ear when he was three in 1991. As a kid and teenager, he struggled to find understanding from his peers to talk about his hearing conditions and needs. It undermined his self-esteem. “How do I explain that thing on my head to the girls?” David recalled the persistent thought that made him a shy and uncertain guy back then. The turning point came when he was about 23 years old.

## **Meeting an older CI user was a turning point**

He met an older man who was a bilateral CI user. This recipient opened up David’s perspective with his upbeat and encouraging outlook. David followed him to gatherings where other elderly CI recipients were present. David found that experience life-changing. “It was so incredible to be able to talk about CI and be understood,” David said. The experience at the gatherings switched David’s outlook on his social life.

“*What you believe about yourself is your truth,*” David quipped. He began to believe that he is someone who could

make friends and have a fulfilling social life. He started reaching out to people and speaking up for himself at work. He has since become upfront about his hearing conditions and needs with his colleagues. Little instructions like “*Get my attention first before you speak to me*” opens up the door for colleagues to support him and demonstrate his willingness to make things work. “*It is not their fault that I have a hearing disability and neither is it mine, but I have to take full ownership and responsibility for it.*”

## **His first long-term relationship was another turning point**

Another paradigm shift came when he had his first long-term relationship at around the age of 27. He used to believe for a long time that he was too abnormal in other people’s view to have a relationship. This old belief no longer takes hold of him. He enjoys meeting people and has been active with [Hear for You](#), which pairs up deaf or hard of hearing teenagers with a mentor (who are also deaf or hard of hearing) in Australia.

**“What you believe about yourself  
is your truth.”**



*David is an active member of Hear for You, a support group for deaf of hard of hearing teenagers in Australia*



6

# DEHAHN BROTHERS

*Using  
tech to  
help  
people  
to get  
clear  
masks*



We need people to wear a clear mask. Especially for people who need facial cues in day-to-day communication. Many among us and around us know this. But the lack of a centralized source of clear mask information has hindered many from getting one. **Jacob (Jake) deHahn** and **Patrick deHahn** responded by creating [accessiblemasks.org](https://www.accessiblemasks.org). These two American brothers are cochlear implant users. I interviewed them to learn more about the platform and their cochlear implant story.

### **What's [accessiblemasks.org](https://www.accessiblemasks.org)?**

It's a platform with a short list of clear mask suppliers. The deHahn brothers have curated the clear mask providers according to style, material and quantity. Indicate the requirements (i.e. style, material and quantity) and the platform will display the suitable clear mask provider.

### **It does the legwork**

The platform does the cherry-picking for clear mask shoppers. Instead of them browsing through Google, Amazon, Etsy and Facebook groups, the deHahn brothers have done the legwork on their behalf. They've researched the clear mask styles, materials and prices before shortlisting the providers. So the clear mask shoppers just need to choose among the best.

So the next time someone says to the deHahn brothers "*Your clear mask is so cool! Where did you get them?*", the conversation doesn't stop there. It could continue at [accessiblemasks.org](https://www.accessiblemasks.org). And, ideally, ends with them getting a clear mask.

### **It started from sporadically sharing links**

Jake is a designer at a small marketing technology startup in San Francisco while Patrick is a freelance journalist (most recently, he was a news curator at Quartz, a global economy news organization).

When the COVID-19 pandemic hit earlier this year, Jake was quick to adopt clear masks. He even made his own clear masks. Though his goal is to have those in his communication circle, and eventually everyone else, wear one themselves. He began a link directory in his Instagram bio to clear masks he found but it was ineffective for mass-sharing. Patrick then suggested that they purchase the web domain [accessiblemasks.org](https://www.accessiblemasks.org), which happened to be available, and set up a website with it. The brothers soon kicked it off with their design and editorial skills respectively.

### **Advocating for their hearing needs as a second nature to them**

The deHahn brothers have practised advocating for their hearing needs since

they were kids. 24-year-old Jake had his profound hearing loss diagnosed within days after birth; 29-year-old Patrick got his diagnosis when he was 9 months old. Both their parents have normal hearing. Jake and Patrick both wore hearing aids until they were fitted with a cochlear implant at age 4 and 11 respectively.

Jake used an FM (frequency modulation) system throughout his school life up until college. He mostly had small classes at college since they were studio/design courses. For lecture-style classes (which he had only once a semester), he enlisted a CART (communication access real-time translation) reporter.

Patrick has been equally vocal about requesting accommodations for his hearing needs. He made it a practice to discuss accommodations that he'd need with his teachers or the disability services coordinators before the start of a school year. Such accommodations include having his teachers wear an FM microphone, peer note-takers, and the occasional CART service.

They credited their parents for empowering them to speak up for themselves.

*“They weren’t necessarily holding our hands all the time but they’re always supporting us from behind,”* Jake said.

When the need for people wearing a clear mask arises, they’re more than ready to speak up about it.

### **At the workplace**

At his (remote) work with the marketing technology startup, Jake managed to get his employer to employ otter.ai, a Zoom plugin that provides real-time captioning and transcription recordings. For his journalism work, Patrick would request to have his interviews and calls done over a video platform. He also asks for clarification, sends follow-up questions and reviews the meeting notes over the email are some of the little steps

to make sure he doesn’t miss out on anything important. When it comes to getting support at our workplaces, Jake stressed that we have to be persistent.

### **In social settings**

They don’t shy away from being upfront about their hearing needs in social settings too. “If I can’t understand you, I’m going to make sure you know,” Jake said. He will sit or walk on the right side of his friends in an outing. He never had issues having people respect his hearing needs. Noisy places like bars, though, are just hit or miss.

Patrick described his approach as being transparent and easy-going. He may tell whomever he’s meeting that he needs to sit on one side to better hear them. And if he misunderstood what someone said, they’ll clarify.

*Their message for you and me*

**“Being deaf is a part of who you are but not all of who you are! It makes you a more empathetic and unique individual -- for me, it has been a driving factor for my career and personal life.”**

*- Jake dellahn*



**“Do the best you can.  
Be confident, stand up for yourself,  
and don’t let your deafness hold you  
back. Your hearing loss and your  
cochlear implant are just a part  
of your story -- relationships and  
opportunities will come your way  
and respect you the way you are.”**

*- Patrick dellahn*



7

*Survived Medical  
School, Earned  
PhD & Teaching  
Medical Students*



**Dr. Irma Isa**

She stared at her blank notepad while her batch mates were scribbling the instructor's messages on their notepad to the brim. It was another trying clinical round for **Dr Irma Isa**, who is currently a Pharmacology lecturer and a cochlear implant (CI) user from Malaysia. She was a third-year medical student on a government scholarship at University College Dublin (UCD). She struggled to grasp her instructor during the clinical rounds. Her hearing level had dropped to the extent where hearing aids were of little help, especially in a bustling hospital environment. Receiving a cochlear implant at the end of her third year of medical school was a gift from God, Dr Irma shared in an interview via email correspondence.

### **CI as the Lifebuoy During Her Medical School Years**

She received her cochlear implant in late 2018 under the National Cochlear Implant Programme by Malaysia's Ministry of Health. It could not have been timelier. It was right before she entered the phase of bedside teaching (student and instructor attending the patient's bedside to discuss or demonstrate a clinical procedure) and

history-taking with patients (taking down a patient's medical history).

She also received help from the Students Support Office at UCD. They had made special arrangements to accommodate her hearing needs, like arranging for her to examine a patient who did not require auscultation (examining a patient with a stethoscope). They had been instrumental in helping her finish her medical study in time.

### **Pivoting to the Academia (From the Hospital)**

Though she found that hospital environments aren't optimal for her to deliver her best. The lack of educated perception among the public (in Malaysia) towards medical professionals with disabilities and her hearing needs convinced her to build her career in the teaching field instead. She went on to complete her master's degree (in Pharmacology and Toxicology) in the next two years and her PhD (in Human/Medical Genetics) in another five. She's been a Pharmacology lecturer at a private university in Malaysia for close to four years.



## **First Detected with Hearing Loss at Age 15**

Dr Irma's hearing loss was first detected when she was 15. She failed to respond whenever her mother called her from behind (without facing her). She had since taken several hearing tests. About a year later, after a few rounds of hearing tests, she was diagnosed with bilateral progressive sensorineural hearing loss. It might have been due to genetic reasons. Both her mother and maternal grandmother have a similar pattern of hearing loss.

Having an immediate family member who is also hard-of-hearing (HOH) has helped build a fortress of self-esteem in Dr Irma. She finds solace in pouring out her feelings to her mother when feeling vulnerable due to her hearing condition.

## **Opening Up About Her Hearing Needs at the Workplace**

Having an emotional safety net at home empowers Dr Irma to be open about her hearing needs in the workplace. She lets her employers know about her hearing condition upfront and has received encouraging responses. The interviewer for her current job, Professor Mike the faculty head from Ireland, was all the more impressed after learning about

her hearing condition in the interview. She remembered Prof. Mike saying, "There is no reason to not consider and help you get this job."

But it wasn't all rosy. During her housemanship 10 years ago, she disclosed her hearing condition to her colleagues and received reactions that did not sit well with her. It took her time and courage to recover from that experience. This leads to Dr Irma realising the need for the public to understand that the deaf and HOH people could bring much value to the table when given the proper support.

## **Advocating for the HOH & Normalising Hearing Loss**

She has since been more proactive in building such awareness within her sphere and capacity. Earlier this year, she co-wrote an open letter to Malaysia's largest English daily paper to shed light on the communications barriers that the hard-of-hearing experience as we wear masks as part of the safety precautions against Covid-19. Her hope is that hearing difficulty will be normalised like how poor visual acuity is generally accepted and well accommodated.

## Life Outside of Work

Besides being an academic, Dr Irma is a mother of four - three boys and one girl between 9 and 2 years old. She enjoys spending quality time with her family, cooking, reading and writing. She also appreciates being able to hear her children, with the help of an aqua kit, when playing with them in the water.



*Dr Irma receiving a certificate of appreciation for her work.*



*Dr Irma is a mother of four.*

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# *Dr. Michelle Hu*



*The audiologist  
who's a patient  
herself*

A limitation points us to our potential. At least that's how it is in **Dr. Michelle Hu's** experience. A bilateral cochlear implant (CI) user, her experience dealing with hearing loss has led her to a vocation in paediatric audiology. Currently residing in California, she's actively spoken out about the challenges living with hearing and how she deals with them. Not only is she living with her hearing loss with dignity, but she's also been impacting lives by doing so. I interviewed her to find out how you and I might do the same.

### **Michelle's hearing loss was progressive**

Michelle was born with a mild hearing loss associated with Pendred Syndrome and enlarged vestibular aqueducts (EVAS). She started wearing hearing aids at age 3. The hearing aids became less effective each time her hearing levels dropped. She experienced the first drops in hearing when she was in elementary school. The last drop was during her senior year of college. It led her to CIs because hearing aids were no longer a helpful option. She was implanted in her left side during her

third year of graduate school in 2008. She went bilateral three years later.

### **That didn't stop her from having a life**

Michelle grew up as a sociable kid. She recounted times when she'd tuck her hair behind her ears to show her hearing aids off. When someone asked, she'd show them the switches and batteries, how she puts them on and tell them "Now I can hear!" Michelle believed that the more she talked about it, the more ownership she took, and the easier it became.

Michelle also credited her positive experience growing up to her parents and teachers. Her parents emphasized that hearing aids were just something she happened to need like how we need seat belts in the car. Michelle's teachers even set up a session specifically for her to share with her classmates about her hearing condition and the hearing aids.

### **She lost her hearing further & found her future in audiology**

Michelle went on to attend Case Western Reserve University in Cleveland, where she majored in Sociology and Chemistry. In her senior year of college in 2005, she experienced another drop in her hearing level. It was the latest drop since the last one in elementary school. While waiting to test her hearing after this event, her mother suggested that she'd make a good audiologist given her first-hand and frequent encounter with the process. Michelle said 'Yes.' Especially since she hadn't figured out the next step after college.

It's the answer to her post-graduation plan. She applied to the doctorate of audiology programme at the University of Akron that fall. She graduated in 2009 and has since been working as a paediatric audiologist.

### **She has her share of anxiety and frustration**

It's important to see that Michelle is a human, like you and me. She's had her share of moments caring about how others perceive her cochlear implants and being frustrated in some situations. She cared on some first dates and her wedding day. She also cared when she was freshly postpartum trying to make new friends with fellow mothers at a noisy gathering. She wishes she

didn't have to focus to listen in noisy environments and miss out on fast and hysterical group conversations. Maybe that's a vanity issue - but who doesn't have such moments? Nevertheless, she embraces them with strides.



### **But she stands up to them**

She showed her husband her CIs on their first date. And her husband loved it. He loved how direct she was with her dating intentions and was attracted to her confidence. Today, they are proud parents of two girls - 2.5 years old and 1 year old respectively.

### **She runs a gem-packed Instagram account**

Outside of work, Michelle is using her voice as an experienced paediatric audiologist and as a CI user to offer support to those in need. She created an Instagram account ([@mama.hu.hears](https://www.instagram.com/mama.hu.hears)) to share her experience living with hearing loss and CI in January this year. Today, eight months later, she's made over 160 posts filled with personal stories, tips and insights for CI users/candidates and parents of one. The account has almost 2,000 followers - many of whom are CI users who'd chip in with their stories and tips in the comment section of Michelle's posts.



*Michelle  
and  
daughters*

## **“It’s about what we can do with it.”**

One takeaway she has for you and me here is that it’s normal for us to sometimes feel self-conscious about our CIs. It’s about what we choose to do with it. Do we choose to rise above and define it (instead of letting it define us)? Could we take responsibility for it and educate others gracefully? Don’t let it have power over ourselves. **Rather, discover what we CAN do with it - then figure out what we need and figure out how to ask for it - or create it ourselves!**

9

*Not Shying Away  
From Making  
Things Work*



**“No problem without a solution can exist.”**

*- Ece's Grade 6 teacher*

That's the motto that Turkish cochlear implant (CI) user **Ece** (pronounced as “**Ai-jeh**”) **Saygi** lives by. Ece's life journey is characterised by a series of problem-solving, even at times ground-breaking, events. She was the first child to receive a cochlear implant in Turkey. She got herself into one of the top universities in Turkey. She secured a student employment role at the Cochlear global headquarters in Sydney while on an exchange programme. She currently resides and works in Switzerland, where she encounters a whole new environment and culture.

### **The first child in Turkey to receive a CI**

Born in 1991, Ece was born hearing but experienced profound hearing loss due to a fever when she was 1. The cochlear implant was then largely unheard of (since the FDA only approved the use of CI in children in 1990). Her mother, who was an air stewardess with Turkish Airlines, learned about CI on a work trip to South Africa. However, CI was not yet available in Turkey. And there was not yet a surgeon who had been trained for the implantation in the

country. It was after a series of special arrangements that Ece was implanted at age 4 in her right ear.

A German CI surgeon made a special trip to Istanbul, where Ece was in, to perform the surgery. The surgery, the first-ever done on a child in Turkey, was watched by Turkish ENT (ear, nose and throat) doctors who were then being trained to perform CI surgeries. Ece's trailblazing CI surgery has helped inspire support by the Turkish government to CI candidates in the country. For instance, cochlear implant users in Turkey receive a free speech processor upgrade every seven years.

### **Putting in the hours to catch up on lost learning time**

Upon receiving the CI, Ece continued the disciplined speech training she had had since age 1. Her training was laser-focused on helping her catch up in terms of skills development. She never played with conventional toys like Barbie dolls. Instead, she mostly played spatial games involving numbers and pictures. The stringent training set her up for a successful transition to a mainstream school in Grade 1.





### **Speaking out for her hearing needs in the classroom**

In primary school, Ece's parents made it a point to inform all her teachers about her CI and that she would need to do some lip-reading. Ece picked up this example and practised it in her high school years. She would request her teachers to try to only give instructions when facing the class, especially when particular teachers had the habit of talking while writing on the whiteboard. These were all to make sure that she got the most out of each class. Her hard work paid off when she got admitted to the Electrical & Electronic Engineering programme at Koç University, one of the most competitive universities in Turkey.

### **Going the extra mile at university classes**

At Koç University, the environment was more challenging due to the larger size of the lecture theatres and the lack of optimal acoustic setup then. Ece oftentimes struggled to keep up with the fast-paced classes. Like in any other situation, the problem-solver Ece focused on the solution. She would request each lecturer for additional learning hours with them outside the class hours. Some of them complied. She would also ask for notes from her classmates and commit to a rigorous self-study routine.

### **Carving a work opportunity for herself while on an exchange programme**

In her third year of university, Ece joined an exchange programme in Sydney. She spent a semester at Macquarie University, which neighbours Cochlear's global headquarters (HQ). She reached out to Cochlear for an internship opportunity. Although there was no existing internship opportunity for a student like her then, the Cochlear HQ agreed to create a student employment role for her. For four months, she worked at Cochlear HQ while attending classes at Macquarie University. This opportunity also led to a one-month engineering internship in Cochlear Technology Centre in Belgium upon her return from the exchange programme.

### **Advocating disability support programme at her home university**

At Macquarie University, Ece experienced what a comprehensive disability support programme is like. The university provided her with assistive devices like speech-to-text software and an FM system and made sure the lecturers were informed of her hearing needs - all free-of-charge. The experience deeply impressed Ece and convinced her that her university back at home should be providing similar support too.

Upon her return from the exchange programme in Australia, Ece shared with her university about the disability support services that were made available to her at Macquarie University. She requested that the university also follow suit. Though the request was not materialised, Ece found herself a private sponsor who would cover her assistive devices expenses for the rest of her university years.

### **Making a switch in her career path**

Upon graduation from university, Ece realised that she was not inclined to take on engineering jobs. She preferred something more dynamic and people-facing. Thus, she got her first job in the wind services support capacity with a large American power company

in Istanbul. The problem-solver Ece relished the fresh challenges that this job presented each day.

She stayed with the company for over two years before relocating to Switzerland to join a Switzerland-based international energy and infrastructure company, in early 2020. She currently takes on a Business Services Specialist role there. Since moving to Switzerland, she has been diligently working on her German language, which she needs to use at her workplace and in her new living environment.



### **Making social life work for her**

Ece is also very solution-centred in social settings. In noisy environments, she would make sure that the person(s) she speaks with are aware of her hearing needs. She would request that they speak more slowly and not face away from her so that she could read their lips. She has found that being transparent about her needs helps others to help her.

Ece is a living example of what a can-do spirit is like. The cochlear implant technology has opened the door to the hearing world that was once closed to her. But it is the strong family support and the palpable can-do spirit that has seen her go such a long way.



Ece at Cochlear HQ in Sydney, where she undertook a student employment role.



Ece and family.



*Ece and friends.*



*Ece and husband.*

# MIMI (AND HER CI- USER SISTERS)



*A Candid (Yet Optimistic) Take On  
Their CI Experience*

Earlier this year, a six-minute YouTube video created by 24-year-old Filipino cochlear implant (CI) user **Joanna Camille Chio (known as Mimi)** left a deep impression on me. In [the video](#) made for a webinar hosted by the International Federation of Hard of Hearing (IFHOH), she shared helpful perspectives we could have about CI, like how being upfront about her CI has helped her find kind people around her.



Mimi's humour and self-deprecating jokes made the video both uplifting and amusing. Mimi, who currently works as a Design Intern at a multinational digital marketing agency, has two sisters who are also CI users.

### **Three CI users in the Chio family**

Mimi, the third child in the Chio family of six, is the second in the family to be diagnosed with profound hearing loss. The firstborn, a daughter, has normal hearing. The second child (Anchette) was the first in the family to be diagnosed with profound hearing loss. Then came Mimi and Kim, who were also similarly diagnosed as a kid.

The cochlear implant was largely unheard of in the Philippines when the Chio sisters were diagnosed with profound hearing loss in the mid-1990s. The Chio parents sought high and low, including making a trip to Hong Kong to check out a costly hearing aid, before learning that CI was available in Manila, the capital of the Philippines. Mimi and her two sisters underwent their CI surgeries around age 2 and 3 respectively.

### **Getting prepared for mainstream schools**

Following their respective CI surgeries in the span of six years, Mimi and her sisters attended five years of intensive speech therapy. This set them up for successful transitions into mainstream schools from Grade 1. Their parents made it a point to keep the school principal and teachers informed about their CI and the accommodations they would need.

Mimi picked up the habit of keeping the people around her informed about her CI and carried it with her to university. She made sure all her lecturers and friends were informed about her CI at Ateneo de Manila University (one of the top three universities in the Philippines), where she pursued a bachelor's degree in Information Design. At each lecture or tutorial, she was given a front-row seat to make sure she could keep up with the classes.



*Mimi and her family*

### **Strong family support as the backbone of her CI journey**

As is the case with many CI users featured on past CI Project interviews, strong family support instills in Mimi proper perspectives of her CI. Having two sisters who are also CI users by her side made CI normal early on. Mimi's mother was never embarrassed about her daughters' CI. She would often encourage Mimi to speak to parents who are considering CI for their children. The experience has helped Mimi to understand fears and assumptions people may have about CI. That has equipped her to advocate for CI in a way that touches people's hearts (as you could see in the six-minute YouTube video mentioned in the opening paragraph).

### **Not a journey without struggles**

When you see Mimi's happy-go-lucky temperament, it is tempting to think that she experiences no struggles. Mimi struggles when it comes to group conversations. In a busy environment like a cafeteria, she would try her best to keep up with the conversations. But there are times when it is simply beyond her. Mimi noted that while requesting repetition or clarification is a way to go, it does take courage to do so. Because while people are generally understanding, it could sometimes feel pesky. It does take practice to get better and more comfortable at it.

Both Anchette and Kim (Mimi's elder and younger sister who are also CI users) share that sentiment.

Anchette, an Advertising Arts graduate from the University of San Carlos in the Philippines, currently works with her mother to support the family's business. She has had difficulty in acclimatizing to languages other than English and certain speaking styles. This poses a problem because the people around her speak Cebuano and Tagalog apart from English. This means she misses the opportunity to make conversations and mingle with others freely and independently. She confessed that she would sometimes ponder how things might have been different if she were born hearing.

Kim, the youngest in the Chio family, currently pursues a bachelor's degree in Restaurant Entrepreneurship at Ateneo de Manila University, where Mimi got her bachelor's degree. Kim speaks fluently and even appeared on a [student-produced cooking show](#) (she ran through the viewers how to make Chicken N' Waffles in the nine-minute show). But when in new environments, she would appear to be less extroverted.

Kim would be more cautious of what she says and would only talk when asked to. Oftentimes when conversations erupt in laughter, she is not sure what to make of it and resorts to smiling bitterly. She has found herself in such situations more often since Grade 8 when she transferred to a bigger school. Meeting new people more often also means higher chances of meeting people who may not be

accommodating enough to take in her requests for repetition or lipreading.

### **Support system: The practical need of the HOH today**

Support system - that sums up what Mimi believes every hard of hearing person needs more of today. A strong support system within the family is instrumental to the shaping of the high-calibre young adult she is today. Earlier this year, she joined HOH groups like the International Federation of Hard of Hearing Young People (IFHOHYP). She intends to be more involved in groups like this and a voice of support to those who need it.

Anchette and Kim echoed that. They pointed out that there is a lack of proper CI-related support networks, at least in the Philippines. Kim particularly suggested having events, locally and internationally, where hard-of-hearing people gather and meet. As we get to know each other, we could form support groups that we could count on for encouragement, advice, elevated perspectives of things.

P.S. Mimi's creativity goes beyond her storytelling skills to her terrific illustration skills. An example: ["This Is My Sister"](#), illustrated by Mimi and presented together with Kim to an audience of speech pathologists in 2018.



## *Pursuing his passion in TENNIS*



Cochlear implant was created to empower. But for many, the default perception is that cochlear implant users are constricted in many ways. Some may have reservations about CI users being involved in sports, let alone building a career out of it. Cochlear implant user **John Lui**, a 35-year-old Aussie, does just that.

### **John plays competitive deaf tennis and coaches**

John, a unilateral cochlear implant recipient, undertakes a tennis coaching career and competitive deaf tennis. He represented Australia three times in the Deaflympics games (2005 in Melbourne, 2009 in Taipei, and 2013 in Bulgaria). He was once ranked as high as no. 8 in Men's Singles for International Deaf Tennis. John began coaching tennis part-time in his university years. He founded a tennis coaching business academy, Lui Tennis, upon graduation from university in 2009. His students include individuals of various age groups (five and above) and levels (from beginner to open tournament level).

### **He spent much time abroad growing up**

Born in Sydney with profound deafness in 1985, John was implanted at age 10. John's family frequently moved around when he was younger due to his father's international work assignments. He spent much of his childhood and adolescence in Brunei, the Netherlands and Hong Kong before returning to Sydney when he was 15.

Adapting to a new social environment and culture was one of the biggest

challenges for John. John had his constraints when meeting strangers. Engaging small talks, understanding and cracking jokes were quite tricky growing up. He needed a more controlled environment when conversation flows more structurally and predictably, which don't often happen with small talks and jokes. He felt more comfortable in staying with just one friend most of the time.

### **He didn't set out to be a pro player and coach in tennis**

John's path to becoming a full-time tennis coach isn't linear. He graduated with a double degree in Bachelor of Social Science and Bachelor of Laws from Macquarie University in Sydney, Australia. Clueless about what he wants to do for a living, he chose to study law for the prestige associated with the field. "I thought it'd be cool when people learn that I study law at parties," John quipped in the Zoom call I had with him.

He began coaching tennis part-time during his third year in university. He turned his coaching into a vocation when he graduated from university in 2009. He is the first profoundly deaf person to become a qualified Tennis Australia Club Professional coach. When John coaches, he puts on the CI speech processor. But when in a game, he takes it off because there's a high chance that the speech processor falls off when he serves the ball due to the head movement.

### **He's also serving the deaf and HOH at Hear For You**

In 2013, John found out about [Hear For You](#), an Australian-based non-profit organisation aimed at supporting deaf teenagers. They run mentoring programmes, career workshops and community outreach events. His first involvement with the organisation is through a mentorship programme in which he served as a mentor. Four months into the mentoring programme, he was offered an opportunity to assume the New South Wales (NSW) State Manager position within the organisation. He took the opportunity and has been serving until today. ([David Romanowski](#), a CI user featured earlier, is also a long-time mentor for Hear For You)

### **John: “*Misconceptions about CI hinder meaningful change.*”**

In his involvement with Hear For You, John observed that various reasons within the hard of hearing (HOH) community has hindered the community from being able to drive effective and meaningful change in the mainstream awareness of deafness. Beliefs like CIs are a magic fix or that CI users don't need any additional help creates confusion and misconceptions around the help they need to perform at their best in the mainstream community. It's difficult to find, let alone bring together the many hundreds and thousands of CI users in a way to create proper change.

When John isn't coaching or running Hear For You activities, he is at home spending time with his wife and their two daughters, aged four and two respectively.

Enjoy this one-minute video featuring John's life story produced by Hear For You:

[https://youtu.be/0rMrLX\\_fvJc](https://youtu.be/0rMrLX_fvJc)

12

# *Her Path to Self-Acceptance & Self-Belief*



Receiving a cochlear implant (CI) at age 2.5 gave Singaporean **Kai Lin** a new lease of life after she was diagnosed with bilateral profound hearing loss at age 1. Today, two decades later, she is a young working woman in the island city-state with much to look forward to. Over a Zoom interview, Kai Lin shared how her attempts in trying new things at various stages of her life, while not necessarily pleasant all the time, paved the way to where she is today. Specifically, they paved the way for her self-acceptance, self-belief and equipped her with independent living skills.

### **The onset of her CI journey**

Kai Lin has been a unilateral CI user since she was 2.5 years old. It was suspected that she had profound hearing loss due to a high fever when she was one year old. Apart from a stint at a kindergarten dedicated to kids with hearing loss, she had been mainstreamed throughout her formal education journey.

Navigating the black-hole question: “Are you really deaf?”

At school, Kai Lin had access to support resources like the FM system and after-school tuition provided by the schools. They helped her to fare well at her studies. But, in the meantime, she first encountered questions concerning her identity: is she deaf or is she hearing? Or is she none of them? Once, a schoolmate asked her, “How can you be deaf when you can hear?” She wondered too.

### **Navigating social life: “Do I belong here?”**

Outside the classroom, Kai Lin picked up Chinese and Modern dance and joined the dance club at her school. She made appearances with the club at various public occasions, like the Youth Olympic Games (YOG) opening ceremony and Singapore Youth Festival (where her team won the Gold award). However, her hearing condition came in the way when she couldn't hear her teammates well and they did not want to repeat themselves. Such encounters didn't sit well with her.

### **Elected as a Student Councillor:**

***“Maybe I actually have more than what I could see in myself”***

Kai Lin also participated in the selection camp for Student Council in her junior college (a pre-university institution). She had to go through a round of interview (in which she disclosed her CI upfront), the selection camp and to carry out a public campaign (publicising herself to the whole school). She eventually got through it and was elected a Student Councillor. Reaching that stage required popularity besides the guts to take part and achievements to qualify in the first place. This helped Kai Lin realise that there might be something that others appreciated about her, which she had not.

### **Living alone for the first time: Affirming her independent living skills**

Kai Lin was appreciative of her supportive family and the exposures in her school life. But she felt that she lacked the opportunity to exercise her

agency in a real-world environment. That changed when she went on a five-month exchange trip to Switzerland. It was her first time living apart from her family. She took the opportunity to visit 18 countries, two of which were on solo trips. She learnt to feed herself, to take care of her belongings and to make decisions for herself. This was an affirmation that she could fend for herself and to live the way she wants to.

### **Mingling with kids with CI: Normalising her CI user identity**

Kai Lin had not had much interaction with other hard-of-hearing people most of her life. It was until her final year at university did she start to involve herself in the larger hard-of-hearing community. She joined a social service club at her university, where she taught kids with CI. Seeing them having fun and even being mischievous helped her to see people with CI, like herself, as normal beings who just happen to have CI.

### **Her hope: Knowing more HOH people**

Kai Lin advocates for the sharing of knowledge and tips among young deaf adults, like you and me, as we navigate major transitions in our 20s and 30s. For instance, getting a job, going into a relationship, and starting a family. For this, she hopes to know more hard-of-hearing people. Even better, to have events among ourselves.

### **Hear more from Kai Lin: Hear Me Out blog**

Kai Lin started sharing her personal experiences, like travelling alone, tackling a job interview and dating on a blog ([Hear Me Out](#)) in early 2019. She has also shared tips for the public, like [how to make communication accessible for a deaf person](#). It is something that Kai Lin wished she had access to when she was younger. It was also through HMO that I got connected to her.



*Kai Lin (left) and her family members*

# **WRITING** *as the life-changer tool*



**“CI recipients can hear conversations,  
music and noise, just differently”**

*-Karina Cotran*



Cochlear implant patients often experience a divide between the hearing community and the Deaf community. For some, it takes time to develop a strong voice when it comes to letting others know about our hearing needs - which can sometimes impair us from being the best that we can be. Cochlear implant user **Karina Cotran** fully understands that from her first-hand experience.

### **Karina wrote a book about her experience living with CI**

Karina is a unilateral CI recipient living in Toronto, Canada. She is currently a Senior Communications Coordinator at the largest Canadian food retailer, Loblaw Companies Limited. She is also an advocate for hearing loss communities who has published a book and runs a blog to share her experiences as a CI recipient. It was a writing assignment in university set her off to a journey of

self-advocacy and advocating for the hearing loss communities, she shared in an interview over a video call.

### **She was implanted at age 7**

Born with moderate hearing loss, Karina was fitted with hearing aids at age three. When she was 7, she was diagnosed profoundly deaf and was implanted in her left ear. She progressed well and had attended mainstream schools from primary school to university. She excelled in her classes despite her hearing limitations and made a group of close friends. Nevertheless, she did experience some teasing about her hearing loss, and also was shy in talking about it with other people. The turning point came when she was attending University of Toronto Mississauga (UTM).

## **Her professor encouraged her to write a book**

As a Professional Writing and Communication student at UTM, Karina was encouraged to write her personal stories. She wrote about her hearing loss. Her work got the attention of her professor, who encouraged her to write more. She did.

She wound up writing seventeen creative, non-fiction short stories on the book - [Hearing Differently: Growing Up With a Cochlear implant](#) - which was published in June 2017, during her last year in university. Writing the book helped her completely come to terms with her hearing loss and realize her aspiration to become an active voice in the deaf and hard of hearing community. It was also a dream-come-true experience for Karina as it is the kind of book that she wished she had had growing up.

## **Advocating for herself at workplace**

Karina is currently a Senior Communications Coordinator at Loblaw Companies Limited. While she is grateful for accommodation provided by her employer, she has her share of struggles (and ways to work around them).

Conference calls are one of the biggest challenges. It would have been easy to feel embarrassed in such professional settings. Not Karina. She stands up and is upfront about her hearing needs to her manager and colleagues. She even detailed her ways of working around such incidents for fellow CI recipients on her blog - [Hearing Differently](#). The biggest CI-related obstacle is not the absence of solutions but how to mobilise the people around them, which takes an initiative from CI recipients.

*From self-advocacy  
into career in*



***NONPROFIT  
COMMUNICATION***

1 in 12,500 people use cochlear implant (CI) according to the United Kingdom Ear Foundation. That's 0.00008% of the world population. The low visibility translates to a strong need for advocacy among CI users. Such a need and exposure to advocacy has laid the career foundation for some among us. **Kennedy Patlan**, an American cochlear implant user since childhood, has pursued her calling in non-profit communication since her university days.

Kennedy was first implanted in her left ear when she was 22 months and in her right ear when she was 9. The cause of her deafness might have been due to complications at birth. The cause wasn't verified.

### **Advocacy as the centrality of her college experience**

Kennedy graduated from Syracuse University with a triple major (advertising, citizenship and civic engagement, and women's and gender studies) and an extensive list of accolades celebrating her academic excellence (Dean's List) and community service (Remembrance Scholar and Newhouse Scholar) in 2018. Her college career was characterised by strong involvement in activism. She was the first Blackstone LaunchPad Engagement Scholar in

which she provided peer mentoring of student ventures with a special focus on social enterprise and civic ventures. She participated in a student-run voter registration campaign that ultimately registered more than 500 students on the Syracuse campus in 2016.

She also assumed a role in various student bodies. Namely, as the Assistant Director of Human Resources for the on-campus public relations firm, as a Syracuse Philanthropy Council member, the Student Affairs Advisory Board member and the New Campus Facilities Board member. In short, Kennedy is a doer with a heart for social issues.

### **It extends to her career**

Kennedy's interest in social causes is also reflected in her career choices. She got her first job in Washington D.C. in which she coordinated campaigns related to diversity and mental health. She switched from her first job to her current job with Ashoka, also in Washington D.C.. She assists the team with identifying America's leading social entrepreneurs, and helps to facilitate programming and support resources for Fellows, as they conquer some of the country's most pressing issues.



### **Her mother plays a role in it**

Kennedy attributes her interest in advocacy to her mother who is an elementary school teacher. Her mother made it a point to explain to Kennedy's classmates about Kennedy's hearing condition in elementary school. Kennedy would later inform her classmates about her CI at the start of the school

year in middle school and high school. She would be upfront about the lip-covering being unhelpful for effective communication. Such experiences empowered her to push for policies that cater to individuals with hearing needs later at university.

### **CI as part of her identity**

An important truth underpinning Kennedy's outlook is that having CI is truly a part of who she is. Her goals have been to make her deafness understood. In a group setting, she makes an effort to make sure the person she's conversing with is conscious of her hearing condition. On a date, she informs her counterpart when she feels ready to do so.

To all of us who are self-conscious about our CI from time to time, Kennedy says that we should, and can do whatever we want. CI isn't holding us back. It's those who couldn't see past our CI that hold us back.

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# *Overcoming shyness & communication barriers*

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Getting a head start is a preoccupation for many parents, especially in Asian culture. It is easy for the parents to feel anxious when they learn of their children's deafness. The anxiety often comes from uncertainty concerning their children's future. The story of cochlear implant user **Kevin Tavianoto**, a 24-year-old from Indonesia, shows us that a CI user could blossom like any other person when shown proper care and support.





### **Implanted and shy**

Born in 1996 in Jakarta, the capital of Indonesia, Kevin was born with profound deafness in both ears. He was implanted on his right ear when he was 14 months old. He attended mainstream schools all along. While he mostly was able to follow the classes thanks to the cochlear implant technology, it was not without a challenge. Juggling between the need to socialize while being different from the other kids during childhood isn't easy. As adolescents, we wanted to feel accepted yet at the same time, we wanted to be seen in a good light. We would not want to be remembered as the one who keeps asking others to

repeat themselves. Therefore, many of us would resort to limiting our social interactions. Hence, we became “shy”. Kevin was in that position.

### **Getting out of the shell of ‘shyness’**

It took some time for him to get out of the shell of ‘shyness’. The quote - “don’t blame yourself for something you could not avoid” - resonated with him and helped him to gradually become comfortable living with a cochlear implant.

His family members had got his back whenever he was down. His friends would try to understand him. He eventually completed his bachelor’s degree in Business Management at Prasetiya Mulya University (Indonesia) in December 2019. The emotional support from his family and friends has helped him stand up to each challenge in the journey.

## 4 STEPS TO NAVIGATING HEARING NEEDS AT WORKPLACE

He is now working as the e-commerce manager at a luggage company, a business run by his family. A workplace presents its own set of challenges. The challenges for Kevin have been to ensure effective communication. He has devised four guidelines to help:

- 1. Recap** - He would repeat the instructions he has received to make sure there is nothing wrongly received or missed out, especially if the task at hand is very important or sensitive.
- 2. Never be afraid to ask questions** - As a working professional, he learns to not let his fear of 'troubling' others override the imperative of getting work done right. When in doubt, ask.
- 3. Take control of the situation** - His colleagues may sometimes speak to him out of sudden, very quickly while he is not yet ready to focus on listening. When that happens, he will ask the colleague to slow down and ask them to resume the speaking.
- 4. Tell the speaker to elaborate** - Sometimes he may still not get it even after the person has repeated himself/herself a few times. Kevin will have him/her to elaborate instead. That helps him collect cues to comprehend what the person wants to convey.



## Kevin's side hustle: A YouTube channel

Kevin runs a [YouTube channel](#) outside of work. He shares practical tips of living with CI (e.g. making phone calls, attending lectures) and commentaries of latest cochlear implant technologies on the channel. He hopes that the information could be of help to parents and individuals with CI. The videos on the channel have been viewed over 5,000 times since the channel was launched in November 2018.

## Strong support is having people understanding and accepting you as you are

Being a CI user makes us an anomaly. People may not have a full understanding or have misunderstandings about our situations. This is why proactive care and support is important, especially when the users are younger. It is also important to have a support system comprising people who already understand us without us explaining ourselves. It is encouraging that we

have many CI users, including Kevin and many in the CI Project Facebook group, are running our own initiatives to speak up and support one another. Here's a [two-minute video](#) featuring Kevin's life journey, produced by Cochlear Southeast Asia.



# *Rising Above His CI User Identity (and vertigo)*



He fell in love with a lady at first sight in 2016. **Lewis Hughes**, originally from England, was then learning how to hear again and was reeling from a permanent loss of balance on his right part of his body following a cochlear implant (CI) surgery a few months prior. This lady was about to relocate to the Netherlands (they met in Sydney). It'd have been the end of his contact with her. But Lewis proposed to tag along. He had no idea what the Dutch language sounds like. Today, they're married and are based in Sydney, where he works at Cochlear's global headquarters.

### **Born in 1988 in England**

Thirty-three years ago, Lewis was born in a small village in North Yorkshire Moors National Park, England. He is the only child of his British father and Australian mother. He was diagnosed with severe hearing loss at age 3 due to Pendred syndrome. He had since been relying on hearing aids, until the CI surgery in 2015 when he was 27 years old.

Back in the early '90s, deafness among children was a major cause of concern for parents and paediatricians. The audiologist, when presenting the diagnosis of Lewis' severe hearing loss, told his parents that his future would be challenging. But it didn't stop Lewis from advancing.

### **His school years: High-performer in & outside the classroom**

Lewis had been in mainstream schools from his preschool years to his university years. He received support with his hearing and speech in his primary school years. But not so much in his secondary school years. It was in those years that he picked up the discipline to self-study, which helped him thrive in his university years. He enrolled at the prestigious University of Liverpool majoring in International Business. He was one of the two of his batch to graduate with first-class honours.

He was also an active figure outside the classroom. He used to surf and participated in several competitions, including the British University Surfing Championships. He was elected to carry the 2002 Commonwealth Games baton through his hometown - that tells you something about his sporting achievements.

He also played music. He has played the piano and the didgeridoo (a wind instrument played using a special breathing technique called circular breathing). He has performed solo and in a wide variety of bands, including jazz, ska, rock and soul. It has somehow worked for him despite his hearing loss.

## **Qualified for CI in 2014 & Making the leap**

He moved to Sydney from England upon completion of his bachelor's degree in 2009. In 2014, he learnt that he was qualified for a cochlear implant under loosened CI candidacy requirements - people with moderate to severe hearing losses were eligible for CI too. He decided to go ahead with the CI in 2015. The decision drew hesitation and concerns from his friends and family members. But he went ahead with the hope that he would receive a better hearing.

## **The bump: Vertigo**

The journey turned out to be more challenging than Lewis had expected. The villain? Vertigo. Due to a rare inner ear condition, the operating CI surgeon had to release fluid from Lewis' endolymphatic sac (a non-sensory organ of the ear) to access the cochlear during the surgery.

The result was that he woke up to a brutal spinning sensation the next day after the CI surgery. The vertigo was so severe that he had been vomiting several times a day. The vomiting caused his eardrum to vibrate, which resulted in deafening ringing in his ear. It was later confirmed that he permanently lost the balance on the right side of his body. His only hope for maintaining the active lifestyle he had led was to compensate

for the loss with the balance on the left side of his body.

Everything seemed to him to be unbalanced and moving around was a real struggle in the first few days after the CI surgery. The situation (minus the vomiting which abated sooner) persisted for over three months. The situation gradually got better as he worked closely with physiotherapists.

## **Nevertheless, better hearing with CI**

Nevertheless, that didn't negate the effectiveness of the implantation. In less than three months after his first CI switch-on, Lewis could hear 100% of sentences (compared to 17% of the sentences with his right hearing aid pre-CI).

Fast forward to six years later to today, Lewis has since met the love of his life, moved to the Netherlands with her, stayed there for close to four years, returned to Sydney where they tied the knot in early 2020. And, he has assumed a brand advisory role at Cochlear global headquarters in Sydney since March 2020. He has also remained active in sports. Apart from cycling to work, he runs and hikes in his free time.

### **Rising above his hearing loss and CI user identity (and even vertigo)**

Undergoing CI surgery as a young adult presents no small psychological (and even physical as in Lewis' case) challenge. Lewis' story shows what rising above our hearing loss or CI user identity is like. He has the confidence that he could be what he wants to be - even when it involves relocating across the globe where he knows no one.

He believes that all of us in the hard-of-hearing community should be more encouraging to one another. And that it helps to have role models who've been in our shoes.

You could check out [the series of blog articles he wrote in 2015](#) where he provided realistic (sprinkled with a sense of humour and pictures) accounts of his journey pre- and post-CI surgery.



*Lewis and his wife (then-girlfriend), Vanessa, spent close to four years in Amsterdam.*

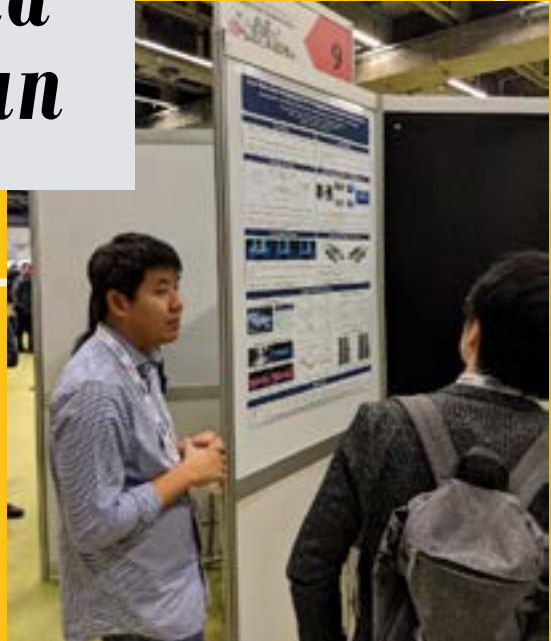


*Lewis and his groomsmen at his wedding.*



*Lewis and his wife, Vanessa, tied the knot in Sydney in early 2020.*

*Not your  
ordinary  
career and  
family man*



Parents tend to worry if cochlear implant can help their deaf or hard-of-hearing children live normally like any other hearing individuals. Will they be able to speak normally? Will they be accepted? Will they be able to be employed? Cochlear implant user **Lionel Heng**'s story provides hope to the parents amidst their anxiety.

### **Lionel has lots of credentials on his resume**

Lionel is a 36-year-old unilateral CI recipient living in Singapore. He is a Lab Director at Singapore's largest defence research and development (R&D) organisation. An alumnus of Carnegie Mellon University, Stanford University and ETH Zürich, he is today happily married with three kids. In an interview over a video call, He revealed his share of struggles as a CI recipient.

### **He grew up with hearing loss and was implanted at age 15**

Lionel was born profoundly deaf in both ears. He used hearing aids until he was 15 when he got implanted in his left ear. He attended mainstream schools from Primary 5 onward. He served the national service for two and a half years before pursuing a bachelor's degree in Computer Science and Economics at Carnegie Mellon University in the US. He then completed a master's degree program at Stanford University and later obtained a PhD at ETH Zurich, which is also Albert Einstein's alma mater. All his advanced levels of education were fully funded by scholarships.



### He struggles in group settings

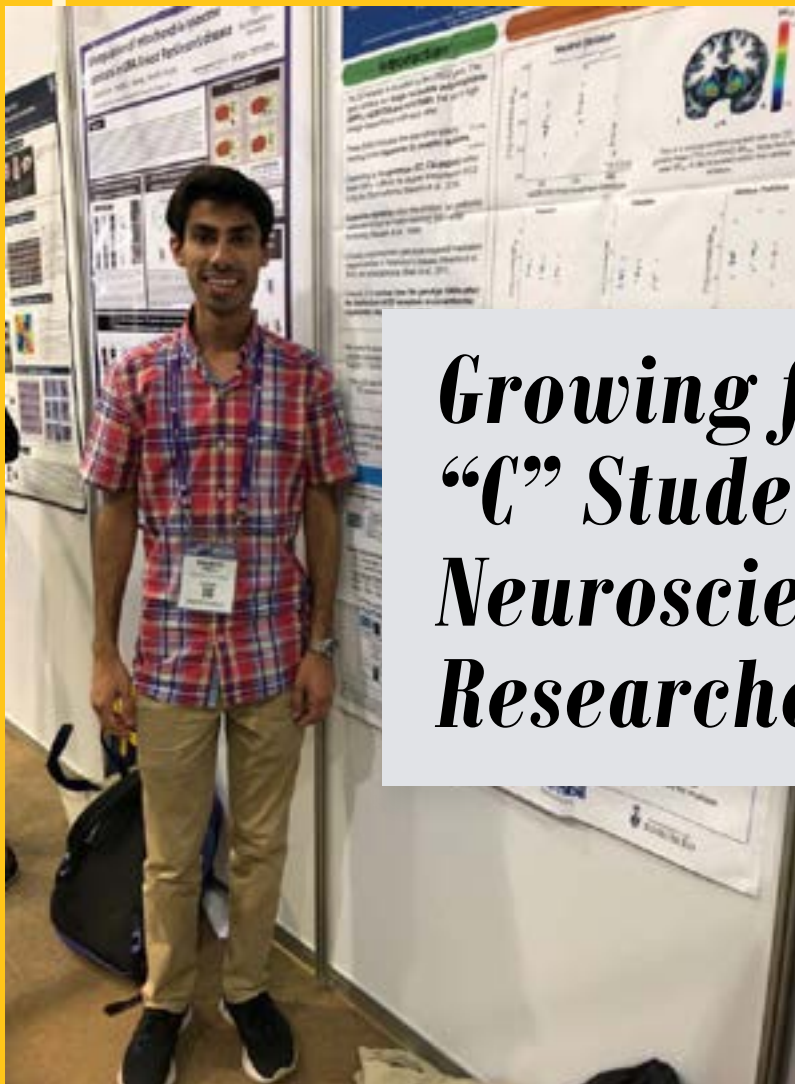
The perfect facade is not without struggle. Lionel shared his struggles in following group conversations and hearing well in noisy environments (albeit the limitations are diminishing with newer CI models). He also wrestled with a lack of self-confidence, especially in public speaking, when he was in university. It was his PhD study that pushed his comfort zone to include public speaking. He needed to develop public speaking skills to cope with oral presentations that came with paper publications as a PhD candidate.

When asked how he overcomes low self-esteem that plagues many CI recipients, Lionel said:

*“Life has so much to offer and I have realized that I can’t just let my hearing pull me down but find ways to work around it.”*

It is easier said than done. Lionel was rejected by his first crush when he was in junior college. But his mother told him: *“Your wife will be a good person because she’ll marry you for what you are.”* And here he is, saying, *“I may have otherwise not met my wife whom I share a happy family with today.”* Lionel has a younger brother, Joseph Heng, who is also a CI recipient.





***Growing from  
“C” Student to  
Neuroscience  
Researcher***

Cochlear implant (CI) user **Mikaeel Valli** from Canada has 15 published research articles that have been cited over 200 times to date. 28-year-old Mikaeel studies Neuroscience as a Medical Science PhD candidate at the University of Toronto. The upbeat young man's journey demonstrates what being humble, positive, and yet, dreaming big despite hearing loss could look like.

### **Starting his CI journey with solid support**

Born with severe to profound hearing loss, Mikaeel was implanted behind his right ear at age 3 in 1996 in Toronto, Canada. He was mainstreamed right from his preschool years. But he was not left to his own devices. He had dedicated auditory-verbal therapists during preschool and itinerant teachers in elementary school to facilitate his speech and communication skills development. The individualised education plan (IEP), which is legally required for special needs students in Canada, also made available additional support for him. These include an FM system, preferential seating, and extended time on tests. Teachers were also made aware of his hearing needs and would adjust their teaching pace when needed.

Mikaeel recalled his teachers and the school staff being very encouraging and supportive throughout their services. They were steadfast and faithful in catering to his hearing needs even when progress seemed minimal. He described himself as a “C” student from Grade 1 to Grade 6. He got a breakthrough in Grade 8.

### **Breakthrough in Grade 8**

By the time Mikaeel got to Grade 8, his language and communication skills had significantly grown. He was introduced to the mainstream English class. He no longer needed the remedial classes. From being preoccupied with keeping up with his hearing classmates, he started taking on challenges like dealing with advanced science projects. Even when his itinerant teacher thought he should continue using the FM system, Mikaeel was confident that he no longer needed it. He was an honour roll student (a recognition for students who achieved high grades) in all his high school semesters. He had progressed to an “A” student and matured to be confident in himself and his abilities.

## **Planning his future**

Mikaeel envisioned himself working in the healthcare field in helping others when considering his career path. He therefore enrolled in the BSc. (Honours) in the Psychology programme at York University in 2011.

Mikaeel was about to spend his first university summer break working at Canada's Wonderland, the country's largest theme park, which would have been his first paying job. But his elder brother suggested that he get experience in something related to healthcare instead to build his resume. Mikaeel took the advice — he quit his hot dog-grilling job at Canada's Wonderland after just one day on it. Instead, he took up a neurosurgery research student position, which he secured after emailing about 100 doctors and scientists.

## **Passion for neuroscience research was born**

That sowed a seed for his career in neuroscience research. He had the opportunity to work with brain surgeons on a research paper. It was a period of accelerated growth. He had

to learn to assimilate difficult ideas independently and to write effectively. He had no prior experience in writing research papers. His supervisor was not always at his disposal as he was occupied with brain surgeries. It took him multiple rounds of re-working before his research paper assignment was accepted by his supervisor and eventually got published.

From that first encounter with neuroscience research, Mikaeel developed an appreciation for neuroscience, medicine and research - all in one. It led to another four neuroscience research positions in the subsequent years. They paved the way to his PhD study which he embarked on in 2016. Currently in his fifth year of study, he is set to complete the programme next year if all things go as planned. He works in a lab that is dedicated to understanding Parkinson's disease through brain imaging.

### **Possibility mindset as a crucial factor helping him to thrive**

When asked if he has any particular words for CI parents or young-adult cochlear implant users reading this story, Mikaeel felt that we could learn to be more comfortable with raising the bar (while remaining realistic). The goal is to encourage effort — every single step on a flight of stairs counts. He recounted being integrated into the mainstream English class in Grade 8 as an example of the teachers raising the bar for him. It was the juncture from which his self-esteem steadily grew, and he has not looked back since.

Mikaeel also credits his parents, AV therapists and teachers for instilling in him the idea that everything is possible if he puts his mind to it. In his early elementary school years, his mother

kept a journal as a communication channel with his teachers. Mikaeel’s mother would pen down questions about his learning progress in the journal. Mikaeel would then pass it to his teachers, who would then share their feedback. Model behaviours like this have reinforced the possibility mindset he embodies today.



*Young Mikaeel in an AV therapy in 1997*

Mikaeel’s favourite quote by Michael Jordan nicely sums up what the possibility mindset sounds like:

**“Obstacles don’t have to stop you. If you run into a wall, don’t turn around and give up. Figure out how to climb it, go through, or work around it.”**

*- Michael Jordan*



*Mikaeel at Bukchon Hanok Village in Seoul, South Korea*

*Uzair  
works at  
Cochlear*



## **Uzair was diagnosed late and had struggled**

The 28-year-old Malaysian was late in his diagnosis of hearing loss. Uzair's mother sent him for a diagnosis when he was still not able to speak/hear properly at age 4. The doctor misdiagnosed him as having a learning disability to explain his lack of learning development. It was until when Uzair was 6 that he was first diagnosed with severe hearing loss. He started using hearing aids then. They did not help much. A more effective help came when he was implanted with CI on his right ear at age 11. He was implanted two years ago, in 2018, on his left ear.

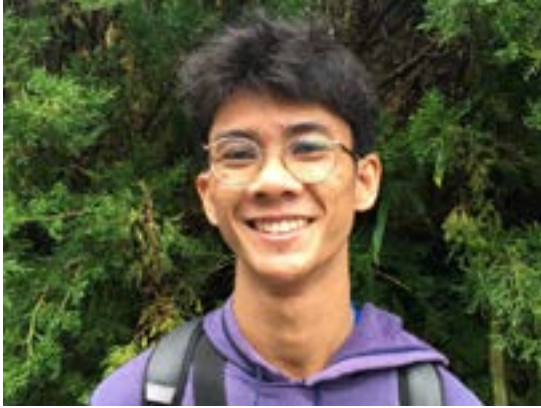
Uzair had been in mainstream schools through his schooling journey. It was a rocky journey. He struggled to keep up with the class. It was not until when he was 11 that he could hear well enough to capture speech. It was then he started picking up vocabulary, grammar and speech. Secondary school years were not smoother for Uzair. His hearing needs and the speech processor

often became the subject of ridicule by his peers. Uzair was struggling not only with studies but also with having friends.

## **Turning point at university**

He was tired of living the downtrodden life. He put in extra effort with three of his best friends in the final year of his diploma programme to pull himself out of the rut. Things turned for the better when he entered university. He pursued a bachelor's degree in Electrical & Electronics Engineering at Universiti Tenaga Nasional (UNITEN), a private university in Malaysia. He met peers from different parts of the country and the world. Their constant care and encouragement brought him out of his diffidence. *"I was afraid that what had happened when I was in Primary/ Secondary school would repeat and think I behave like an idiot, or I may not hear or misunderstand what they say. But my friends refused to stop helping and kept pushing me to be more outgoing and confident,"* Uzair said.





He started to learn to be comfortable under his own skin, and to mind less about others' comments and opinions. Once shy and socially awkward, Uzair grew into a sociable guy known for his goofy manner and his signature broad smile throughout his three and a half years of university life.

### **Joining Cochlear**

He did an internship with Cochlear in Kuala Lumpur, Malaysia during his final year in university. He joined the team as a Graduate Engineer upon graduation. He was later promoted to the Repair Support Engineer role. He has been with Cochlear since March 2017. It was a dream-come-true for Uzair. He has always wanted to improve the living quality of those with hearing loss, especially for the young ones. Uzair is well on track in proving that hearing loss is not going to stop him from living a meaningful life. Our success is



the best response against stereotypes and prejudice targeted at people with hearing loss, Uzair said.

# *Richard implanted*



*after 35 years of  
silence*

Focus on what the cochlear implant (CI) technology can do for you. You risk missing out the wonder of the technology if you ruminate on blemishes, like how the behind-the-ear (BTE) speech processor will look on you and the surgical scar (which is very subtle, if visible at all, thanks to increasingly advanced surgical technologies). That is the key message cochlear implant user **Richard Pocker** shared over a Skype interview.

### **Pocker spent 35 years in total silence before getting implanted**

Pocker is a 68-year-old bilateral CI recipient based in Florida. He first experienced hearing loss after contracting scarlet fever at age 5. He relied on hearing aids since then. Just before his 30th birthday, his hearing loss turned so severe that hearing aids were no longer effective. CI technology was still in its infancy then and was not known to Pocker then. He spent the next 35 years

in total silence. He relied on lip reading throughout the years. It was very challenging — try lip reading a movie with no captions or sound.

### **He built a business in the 35 years**

Pocker was building his business, which involved managing a few dozen employees and attending trade shows — all by lipreading. The internet, which enables text-heavy communication, was not in the mainstream yet. That was in the early 1980s. He had to rely on others to make every phone call for him. He even made every one of his business suppliers purchase a fax machine, which was new and fairly expensive then.

It was hard due to a lack of social support

Social support was not very accessible. Many of the people around him just faded away, unable or unwilling to cope with the new accommodation needed to communicate with him. Besides, he had to accept that his hearing could no longer afford the music experience he once relished. He loved listening to Frank Sinatra, a jazz and pop singer and Luciano Pavarotti, the most famous opera singer of his time.

### **He learned about CI by bumping into a CI user**

He had a chance encounter with someone wearing a new style single-unit CI processor after living in total silence for 35 years. He found that he was a candidate for CI. He jumped at the chance to be implanted in both ears. He underwent the surgery in December 2015 and the switch-on in January 2016, which was a few days before his 65th birthday. Three years later, his life has never been better.

Pocker could now hear his son's voice. His son was 3 years old when Pocker lost his residual hearing. Imagine watching your child grow while you lived in total silence.

### **Life has since been different**

He no longer needs to turn his head when driving to lipread his wife of another passenger. He and his wife have been married for 44 years. He had to resort to lipreading his wife for 35 years out of the 44 years. He can make phone calls, which an activity he previously had to rely on others' help. He no longer feels the need to isolate himself in group meals.

He even enjoys music again. He streams swing (a kind of jazz music) and classical music directly from his iPhone to the speech processor. It took several months of listening after the surgery until the music began to sound like he remembers them. They are still not 100% but not too far from there. He can recognize bird songs he never heard even when he wore hearing aids. He can even distinguish a cardinal from a pileated woodpecker. New problems arise too. He once found himself waking up in the middle of the night to the noise of door hinges. He had to fix it with a precision oil pen. That was a happy problem.



*Pocker sharing about CI to an audience of high school students.*

### **He's on a mission of helping CI candidates**

Like many cochlear implant recipients, he regrets not having been implanted sooner but is grateful for the opportunity to enjoy life to the fullest again. He is on a mission of helping CI candidates move forward with their CI journey. He understands the anxiety and doubts over the uncertainty that loom large when it comes to making the leap of faith to receiving CI. He dedicates himself to be the person whom others can turn to when they find themselves in such a situation.

21

*Cl isn't stopping his  
passion for sports*



I started CI Project with one question:

***“What cochlear implant is meant to be in my life?”***

We all may be using the same cochlear implant technology. Yet, our experience living with it can vary across a wide spectrum. However, there’s one thing for sure - cochlear implant should enable us to live life as we want it to be. What does that look like? While it may look different for each of us, I saw a glimpse of it in a **Ricky Alfred**, a 24-year-old cochlear implant user from Indonesia.

During the day, Ricky works as a Digital Marketing Executive. Outside of work, he’s an avid road cyclist.

Ricky was born in 1997. His parents learned about his hearing loss when he was 20 months old. But it was a year later, after his parents gathered a sufficient fund to cover the costs, Ricky was implanted in Singapore. They remained in Singapore for four months, during which Ricky underwent the implantation surgery, activation of the implant and speech therapy sessions.

Upon returning to Indonesia, Ricky’s parents diligently fostered his speech and language development. He enrolled

in mainstream schools right from day one of his school life. He described his school life as mostly pleasant. There were no major bully incidents besides a less-than-sensible tease about his hearing loss by one of his schoolmates in one instance.

He later attended a private Christian university in Jakarta, the capital of Indonesia and his hometown. He graduated with a bachelor’s degree in Business Management.

Ricky’s transition to the workplace bore a similar note. In the interview for his first job, he neither hid his hearing loss nor revealed it upfront. It was nearing the end of the interview that the interviewer noticed his cochlear implant speech processor on his left ear, which he then explained. He later got the job offer. He is able to function and perform like any of his hearing colleagues thanks to the advanced speech processor technology.

Ricky’s message for everyone reading this is that if you’re feeling down because of your hearing loss. That’s okay. But he hopes his story is a testament that, with proper support, we could still do anything we want.

### Interviewer's (Peng) note

Ricky is the kind of self-assured young man that many cochlear implant parents would hope their children grow up to be. A strong support system is foundational in this matter. A telling example of this support system is that his parents did not limit, but encouraged, him to participate in various sports. As you could see in the photo below, Ricky donned his CI speech processor encased in a waterproof kit. That allays any fear that the sweat might cause damage to the device.



*CI speech processor encased in a waterproof kit on Ricky's left ear.*

Speaking from a risk-averse point of view, having a cochlear implant is a pretty convincing reason to shrink back from trying new things. Yet, the 16 cochlear implant users I've interviewed have shown me again and again that we will want to review our decisions of not trying new things because of our CIs. We can all start with baby steps.

Road cycling? Yes.

Tennis? Yes. (Check out [John Lui's](#) story)

Travel around the world as a TV show host? Yes. (Check out [Alana's](#) story)

Practice audiology? Yes. (Check out [Dr. Michelle Hu's](#) story)

Run a business? Yes. (Check out [Richard Pocker's](#), [Ashlei Powell's](#) stories)

Publish a book? Yes. (Check out [Karina Cotran's](#) story)

Work at a news publication? Yes. (Checkout [Patrick DeHahn's](#) story)

**What cochlear implant is meant to be in your life?**





*Ricky (left) and fellow road cycling group members.*



*Ricky (left) with his girlfriend (2nd from left) and his family.*



*Ricky in one of his road cycling outings.*

*Re-  
implanted  
&  
graduated  
top of class*



Cochlear implant (CI) is an artificial mechanism enabling us to receive sounds. But we the cochlear implant users need to take a proactive step to decipher the sounds into meaningful information to us. In non-silent situations, we need lipreading to a certain extent to facilitate or affirm the deciphering process. Some of us need more support from lipreading due to the differing levels of effectiveness of our CI. When technology has done its part, we need to play our part. Cochlear implant user **Stephen Wright** has learned to play to his part by being upfront about these needs and designed his life around them.

### **Stephen works as an audiologist**

Stephen is currently working as an audiologist at InTouch Hearing, an audiology and hearing aids centre in Ontario, Canada. The 27-year-old Ontario native was first implanted in his left ear at age 4. He was explanted and re-implanted in the same ear when

he was 13 because the previous implant was slowly failing. In 2015, he was implanted in his right ear as part of a study to see how children who got CI at different times performed.

### **He was re-implanted**

Stephen has experienced limitations due to his hearing limitation growing up. He could not play at the plastic slides in the playground, swim or play any water sports while wearing the CI speech processor. It was because CI is susceptible to static electricity when a child slides down a plastic slide and it was not waterproof. He also experienced a whole month of total silence in the month following his re-implantation when he was 13. He could not put on his CI while waiting for the surgical wounds to heal that month. He was effectively cut off from all his friends and family.

### Navigating social life

Even today, he screens his invitations to events. *“If I feel that I am not going to be able to participate due to lack of accessibility, I likely won’t go,”* Stephen shared over email correspondence. For instance, he could not go to drive-in movies (spectators watch movies outdoors while inside their own cars) because there is no subtitle option. He could not join parties at night or take part in campfire conversations because he could not see well enough to lipread. Furthermore, he is usually too tired by the end of the day to listen well. At university, he had a service dog as part of the accessibility support. It helped make his hearing needs visible. His schoolmates would stop by and talk to him about the dog. That kind of first contact helped him to make new friends.

### He graduated top of his class

His hearing needs do not overshadow his talents and strengths. He excelled at school. He completed his undergraduate degree in Biology at Nipissing University (a liberal arts college in Ontario, Canada). He was elected the valedictorian of his graduating class, the class of 2015. [His valedictorian speech](#) at the convocation was greeted with a standing ovation. He later spent 18 months at missions school and trips in the UK, Albania and Uganda for missions school and work. He also completed his master’s degree in Audiology at Western University in 2018.

### He aspires to be a CI audiologist

Stephen aspires to be a cochlear implant audiologist. He believes that he could immediately and deeply empathise with his CI patients since he has been both early and later implanted. He understands the daily struggle that comes with being a CI recipient. He could distinguish what it means to be successful with one’s CI (his left ear) and what it looks like to be not so successful (his right ear).

Looking at the Deaf and hard-of-hearing community as a whole, Stephen believes more needs to be done in terms of bringing the members closer to each other. He believes that we need to advocate for our needs, and intentionally step out to make the connections with each other.



*Stephen and friend showcases cochlear implant speech processors*

*Yat wants to make hearing loss a normal topic*



*“I didn’t know what to do,”* cochlear implant user **Yat Li** said.

***“I want to be myself, I want to take off the mask.”***

Yat is an independent adult with a decent job - a marker of successful outcomes for a Cochlear Bone Conduction Implant System. But he had remained unfulfilled, especially with the mask he had been putting on for years. It was not until 2018 that he took off the mask.

### **Yat was born with microtia and profound deafness**

Yat, a 30-year-old Canadian, was born with microtia that comes with profound hearing loss in both ears. Microtia is a congenital deformity in which the external ear is underdeveloped. It is a condition affecting 1 in 10,000 people. The severity of microtia ranges from Type 1 to Type 4 where Type 4 is the most severe – all external ear structures are missing. Yat had been fitted with traditional over-the-head hearing aids until he was 12 when he got implanted in his right ear.

### **He has to wear prosthetic ears**

Apart from putting on the behind-the-ear speech processor every CI recipient

wears, Yat had to put on prosthetic ears so that he would not attract unsolicited attention to his tiny ears. He would spend 45 minutes affixing a pair of disproportionately large prosthetic ears with adhesive each day. The prosthetic ears refrained Yat from sports activities or being in the swimming pool lest the prosthetic ears drop off. It was not until 2011 that he underwent surgery to affix prosthetic ears to his face with screws that he has ears that look more proportionally sized and allow him to be more physically active.

### **It crushed his self-esteem when he was younger**

Teenage years were especially harsh on him. As an immigrant from Hong Kong who moved to Canada when he was 5, Yat was a minority on multiple fronts. At school, he was a racial minority, a non-native English speaker, a microtia bearer, and a person with hearing loss. Furthermore, he was surrounded by hearing people as he had been in mainstream schools throughout his education journey. He started feeling self-conscious and ashamed of his differences in middle school. He would shun his peers and secluded himself up. Meeting with CHHA was a turning point.

It had been a lonely journey until 2018 when he came to know a support group - Canadian Hard of Hearing Association (CHHA) British Columbia Youth Peer Support Program. He felt welcomed - a refreshing experience for him - and was inspired to take off the mask and be himself. He decided to stop hiding from who he is and stand up to what he had been avoiding - speaking out about his hearing loss and microtia.



### **He wants to normalise conversations about hearing loss**

He started Acoustic Wear in June 2018. Its aim to make it fun to talk about hearing loss and in turn, remove the stigma surrounding hearing loss. Shortly after that, he was offered an opportunity to work at [Wavefront Centre for Communication Accessibility](#),

a British Columbia-based registered charity whose work revolves around providing access and inclusion for the Deaf and Hard of Hearing. Wavefront Centre serves over 14,000 Deaf and Hard of Hearing clients per year by delivering innovative services to achieve full communication accessibility. He jumped at the opportunity and quit his previous job as a Customer Relationship Management (CRM) Manager with a hospitality group.

### **His biggest lesson is to be himself**

Looking back, the perceived risk of being ostracized led Yat to socially self-quarantine. However, it did not turn out any better. Yat became an enigma and was often misunderstood by his peers. “Be yourself,” Yat said when asked what advice he would give to his younger self. “It’s okay to fail, the most important thing is being yourself.”

Being involved in the Deaf and Hard of Hearing community gave Yat a new lease of life. He hopes that more CI users can join him in being part of a support group to help more people reap the benefits of hearing solutions. “It can be very isolating living with hearing loss.”

# Cochlear Implant User Experience Survey Findings

A cochlear implant (CI) experience doesn't stop at restoring functional hearing. Adults and parents of children with hearing loss commit to a CI decision with significant hope. They hope for a life where they could function and enjoy life like anyone else. Therefore, it's insufficient to consider solely the technological aspect of a CI experience. I created a survey to find out how CI users' quality-of-living outcomes, particularly in education, career and social life.

[Scroll the bottom](#) for the PDF (64 slides) if you prefer visuals over words.

## Demographics

Total number of respondents

**35**

CI users aged 18 and above  
(Sourced from CI-related community groups on Facebook & Whatsapp)

Gender



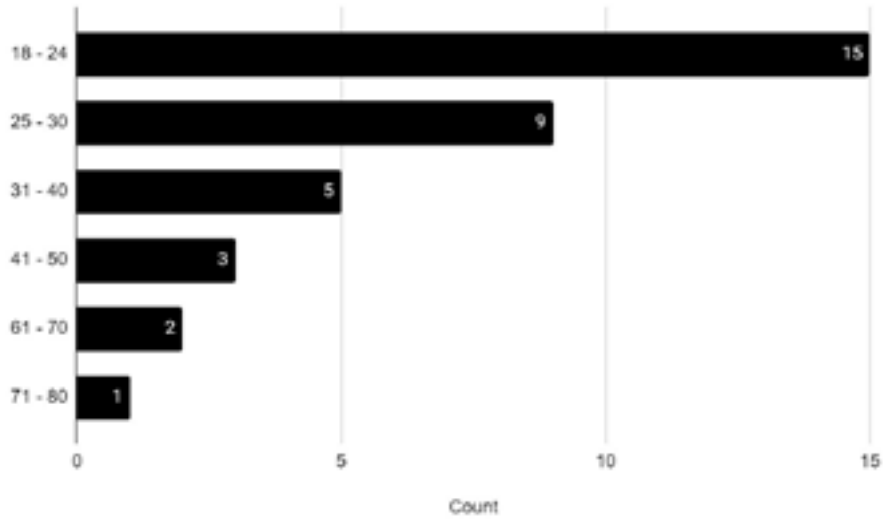
**13**  
(37%)



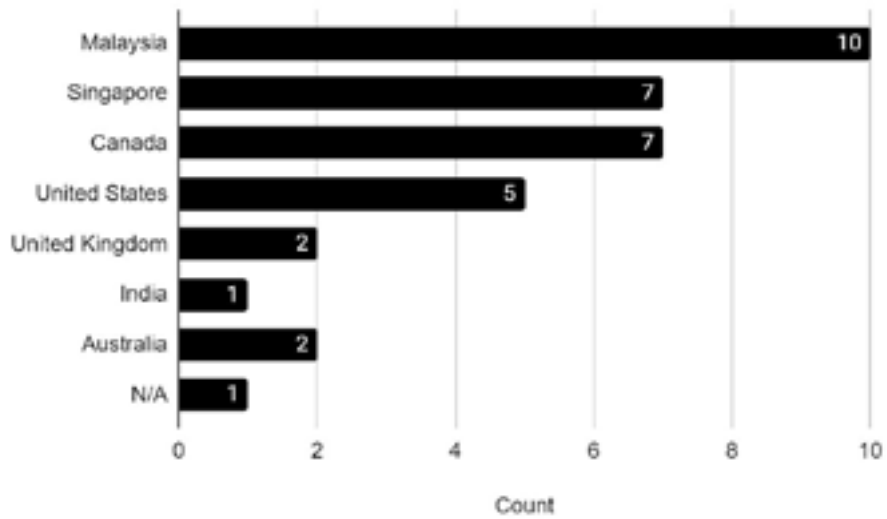
**22**  
(67%)



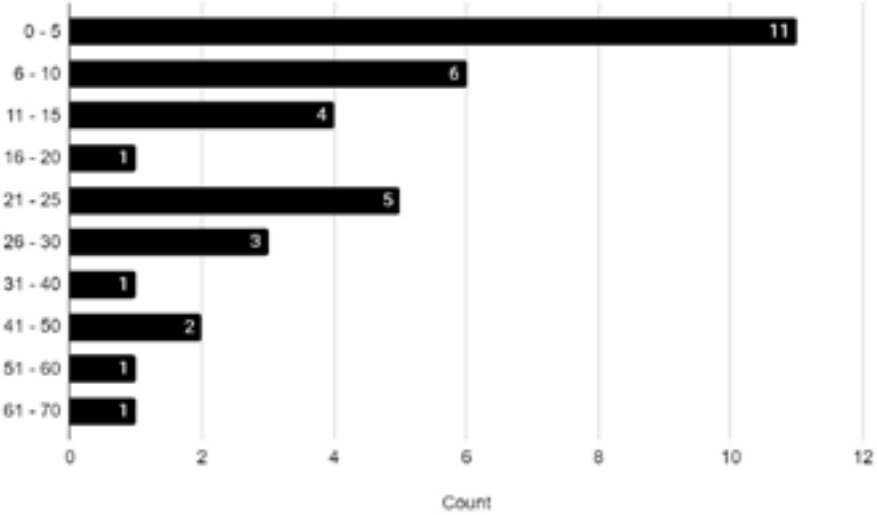
## Age group



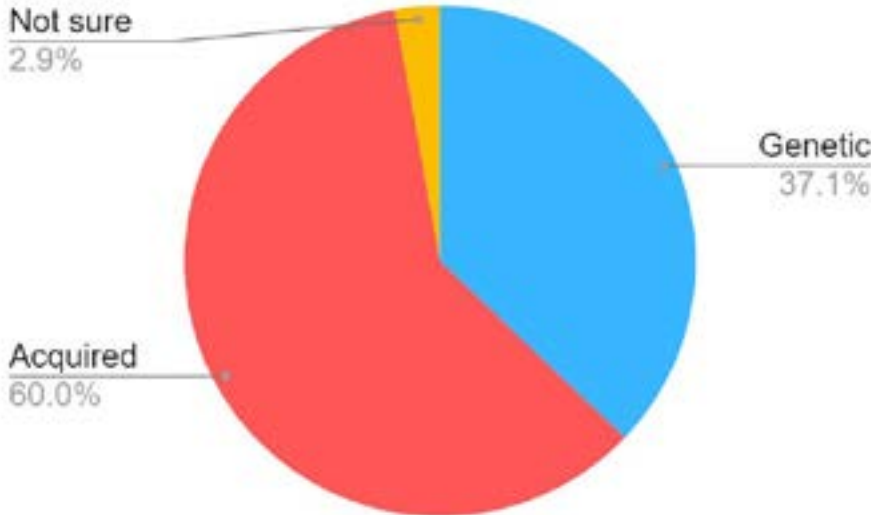
## Country of residence



# Age implanted



# Nature of hearing loss



# Findings

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## Education

The education questions were shown only to those who were implanted below age 18 (22 out of all respondents). The questions measure the correlation between having CI and their experience at school.

63% of them (14 out of 22) attained at least a bachelor's degree. 81% of them (18 out of 22) described themselves as 'having thrived at school' or 'made it through and graduated in time'. 72% of them (16 out of 22) said they were able to get hearing-related support in the classroom.

## Career

The most common field of work the respondents who are working (21 out of all respondents) are in is Health Science (19%). That's followed by Marketing, Sales & Service (14.3%) and Education & Training (14.3%).

## Social

I employed nine inner-dialogue statements and instructed the respondents to rate the tendency (always, occasionally, seldom or never) of that particular inner dialogue.

*Q1 (self-image): "I think about how others would judge me because of my CI (speech processor, surgical scar) or hearing needs."*

*Q2 (disclosure of CI): "I try not to let others know that I have CI whenever I could."*

*Q3 (requesting accommodation): "I worry about asking others to repeat themselves."*

*Q4 (sense of aesthetics): "My CI makes me less presentable/less decent-looking."*

*Q5 (relationship concern): "I worry if I'll ever find someone who could see past my hearing loss/hearing needs and love me."*

*Q6 (socializing): "I like meeting new people but my hearing makes me feel more cautious about meeting new people."*

*Q7 (sense of competency): "I worry if my teachers/peers will question my competency when it comes to leadership in a class/club."*

*Q8 (dynamic at home): "I feel like a burden to my family."*

*Q9 (contact with CI community): "I don't want to have any close contact with the deaf and hard-of-hearing community."*

I compared the results in four ways:

- 1) For those implanted below age 18, the frequency of that particular inner dialogue as a teenager VS. as an adult now
- 2) Those implanted below age 18 VS. those implanted at age 18 & above
- 3) Male VS. Female
- 4) Those in western culture (Australia, Canada, the UK & the US) VS. eastern culture (India, Malaysia & Singapore)

**1) For those implanted below age 18, the frequency of that particular inner dialogue as a teenager VS. as an adult now**

Overall, the respondents have **better social experience today** compared to when they were teenagers.

### **Details**

The tendency for each of the nine inner dialogues either has decreased or remains largely the same today compared to when they were teenagers.

Inner dialogues for which the frequency has decreased:

*Q1 (self-image): "I think about how others would judge me because of my CI (speech processor, surgical scar) or hearing needs."*

*Q2 (disclosure of CI): "I try not to let others know that I have CI whenever I could."*

*Q3 (requesting accommodation): "I worry about asking others to repeat themselves."*

*Q4 (sense of aesthetics): "My CI makes me less presentable/less decent-looking."*

*Q7 (sense of competency): "I worry if my teachers/peers will question my competency when it comes to leadership in a class/club."*

*Q8 (dynamic at home): "I feel like a burden to my family."*

The tendency remains largely the same for the other inner dialogues:

*Q5 (relationship concern): “I worry if I’ll ever find someone who could see past my hearing loss/hearing needs and love me.”*

*Q6 (socializing): “I like meeting new people but my hearing makes me feel more cautious about meeting new people.”*

*Q9 (contact with CI community): “I don’t want to have any close contact with the deaf and hard-of-hearing community.”*

## **2) Those implanted below age 18 VS. those implanted at age 18 & above**

Overall, the two groups of respondents have a **similar social experience**. They differ in only three areas: how comfortable they’re in requesting accommodation, whether CI affects their aesthetics, and whether CI make them perceived less competent

### **Details**

The two groups mostly have similar tendencies for the nine inner dialogues. They differ only in three inner dialogues:

*Q3 (requesting accommodation): “I worry about asking others to repeat themselves.”*

- The **Implanted between age 0 and 18** group has a higher tendency to have this inner dialogue

*Q4 (sense of aesthetics): “My CI makes me less presentable/less decent-looking.”*

- The **Implanted between age 0 and 18** group has a higher tendency to have this inner dialogue

*Q7 (sense of competency): “I worry if my teachers/peers will question my competency when it comes to leadership in a class/club.”*

- The **Implanted after age 18** group has a higher tendency to have this inner dialogue

### 3) Male VS. Female

Overall, male and female respondents have **different areas of concern**. The male respondents have more concern about their relationship prospect and meeting new people. While the female respondents have more concern about requesting accommodation, how CI affects their aesthetics, and having close contact with the CI community.

#### **Details**

The two groups mostly differ in terms of the kinds of inner dialogue they tend to have.

*Q3 (requesting accommodation): “I worry about asking others to repeat themselves.”*

- The **Female** group has a higher tendency to have this inner dialogue

*Q4 (sense of aesthetics): “My CI makes me less presentable/less decent-looking.”*

- The **Female** group has a higher tendency to have this inner dialogue

*Q5 (relationship concern): “I worry if I’ll ever find someone who could see past my hearing loss/hearing needs and love me.”*

- The **Male** group has a higher tendency to have this inner dialogue

*Q6 (socializing): “I like meeting new people but my hearing makes me feel more cautious about meeting new people.”*

- The **Male** group has a higher tendency to have this inner dialogue

*Q9 (contact with CI community): “I don’t want to have any close contact with the deaf and hard-of-hearing community.”*

- The **Female** group has a higher tendency to have this inner dialogue

They have similar tendencies for all the other inner dialogues.

#### 4) Western VS. Eastern Culture

Categorization for this survey analysis:

*Western Culture = Australia, Canada the UK, the US*

*Eastern Culture = India, Malaysia, Singapore*

Overall, the respondents from the **Eastern Culture have poorer social experience** than their Western Culture counterparts. They have more concern, which comes from their having CI, in their social experience.

##### **Details**

There's a significant difference between the two groups of respondents in terms of their tendencies for the nine inner dialogues. The Eastern Culture group has a higher tendency for all the inner dialogues, except one in which the Western Culture group shares a similar tendency:

*Q3 (requesting accommodation): "I worry about asking others to repeat themselves."*

# *What's next*

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There are two ways to move forward from here - to understand the issues better or to work on them.

## **To understand the issues better**

- a. **Employment experience:** to find out CI users' job satisfaction, their access to opportunities and accommodation at the workplace
- b. **Go in-depth with each demographic:** to find out the major concern for users in each age group, gender and region
- c. **Qualitative survey with individual CI users:** to find out the narrative and dynamics at play in their everyday experience
- d. **Longitudinal research:** To find out how their experience changes or fluctuate in different settings and life stages
- e. **Cases with a lack of success:** To find out what factors are hindering the users (who lag behind their CI peers) from achieving the desired outcomes

## **To work on them**

**Education:** To establish a system to integrate CI children into mainstream classrooms

**Career:** To establish a support system for CI users seeking employment or in employment

**Social:** To establish support groups for CI users, especially in regions outside of the US



## PDF slides for visual readers

You may also view the detailed survey results breakdown (more visually pleasing) in this PDF (64 slides)

[CI UX Survey Results Slides \(64 slides\)Download](#)

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You could find more cochlear implant user stories [here](#). You could also read about the author of this survey, [Peng](#).

CI Project collects cochlear implant user stories. I'd like to invite you to join the [private Facebook group](#). You'll receive an update of each new story (about once a month) and will get to interact with the characters of each story there. I'm also looking for more cochlear implant user stories. I'd appreciate it if you could nominate a cochlear implant user (including yourself) for me to write a story about!



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