

## CIICA Conversation: ADULTS WITH CI: ACCESSIBLE BILATERAL COCHLEAR IMPLANTATION 28 January 2025: Summary of the conversation

### Facilitators:

Kathryn Chlosta, unilateral CI User, Netherlands, Wendy Huinck, Associate Prof ENT, Nijmegen, Netherlands, Robert Mandara, bilateral CI User, President, EURO-CIU, Finland, Sue Archbold, Coordinator, CIICA.

27 Attendees from 13 countries: 11 users of CI, several parents of children with CI and a ranged of professionals, including surgeons, audiologists, therapists, and from industry. Live captioning was provided. Participants were from Austria, Belgium, Canada, Finland, Germany, Ghana, Netherlands, Romania, Slovenia, Switzerland, Turkey, UK and USA.

### Introductions:

Sue welcomed everyone, provided some Housekeeping notes and encouraged attendees to also introduce themselves and via the chat room, before handing over to Kathryn as facilitator for the event.

### Framing the Conversation

Wendy began by setting the context for the conversation which she and Kathryn had initiated. *In the Netherlands and many other countries bilateral implantation is only reimbursed for children up to 18 years old. But not for adults. So adults who come for the first appointment, which is the intake for cochlear implant almost always and kind of surprised why they only receive one implant.*

She went on to explain why binaural hearing is important:

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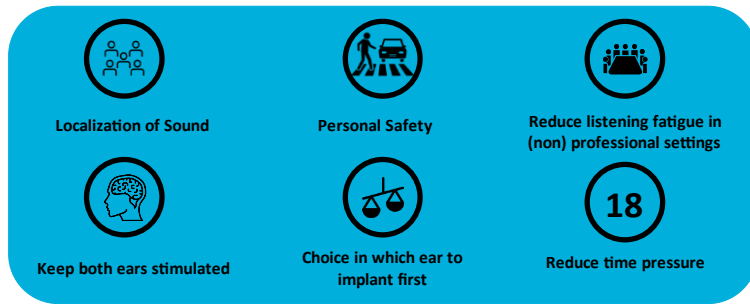
### Why is Binaural Hearing important?

Ears work as a team, and the brain needs them both to best understand speech and tell where sounds are coming from. <sup>1</sup>



<sup>1</sup> Litovsky RY, Johnstone PM, Godar SP. Benefits of bilateral cochlear implants and/or hearing aids in children. *Int J Audiol* 2006; 45(Suppl): S79-91.  
<sup>2</sup> Avan P, Giraudet F, Baki B. Importance of binaural hearing. *Audiol Neurootol*. 2015;20 Suppl 1:B. doi: 10.1159/000380741. Epub 2015 May 19. PMID: 25986698.  
Picture from <https://www.judisonaudiology.com/resources/binauralhearing/>

## Benefits of Bilateral Cochlear Implantation



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Wendy also explained the benefits of bilateral cochlear implantation, which gives binaural hearing and are summarised in the figure above.

*So having two ears improves your ability to understand speech, especially in noisy environments.. And also it helps in the balance and in binaural integration. ....In a busy environment you can easily localise where sound comes from, for example, shopping in a busy city centre and when a friend sees you and calls you. But it is also important for personal safety. So, for example, in traffic or hearing where a car or danger comes from - it is of course very important.*

### The decision to implant the second ear:

Wendy introduced the challenges for clinicians and patients to decide which ear to implant, if providing only one.

*A second implant in the ear that was deaf for many, many years will probably function not as well as the first implant. And this sometimes causes complex situations, we experience that in the clinic. Especially nowadays cochlear implantation is beneficial in people with residual hearing so the combination of the cochlear implant and the hearing aid on the other ear is beneficial. And therefore, we often choose the worst ear for cochlear implant. But in some cases the worst ear might not give the best outcome with a cochlear implant. If there still is an option to implant a second ear at a later time then this is not a problem. Then you can implant that ear later on. If you can only implant one ear the choice becomes more difficult.*

*We also have the age limit in the Netherlands but also other countries. This can be difficult with young people in our clinic with their progressive hearing loss who decided to go for the second implant before they turned 19 even when there was some functional residual functioning in the second ear so. They gave up their acoustic hearing too early, I think. Otherwise it would not have been possible to get a second implant.*

### Reimbursement Systems

The reimbursement of CI in the Netherlands is similar to some other countries and the following image illustrates this:

## Reimbursement CI in the Netherlands



### Children

- Bilateral CI up to and including 18 years of age



### Adults

- Unilateral CI even if bilaterally deaf
- Bilateral CI only in case of:
  - Bilateral deafness caused by meningitis
  - Deaf-blindness
- Patients cannot pay out of pocket as this would be inequitable to those who cannot afford to pay

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Kathryn then asked the participants these questions and began with her own story.

- Is bi-lateral CI implantation **widely accessible** for adults where you live?
- Is bi-lateral CI implantation **reimbursed by health insurance** for adults where you live?
- What is your experience?

*I am originally from the US, but I live in the Netherlands, so I am part of the Dutch healthcare system. In the US, bi-lateral CIs are widely available, but this is not the case in the Netherlands. I'm bilaterally deaf. I have a genetic disorder that causes progressive hearing loss. Because of the genetic disorder, the residual hearing will eventually go away. I wear a hearing aid in the non-implanted ear. So on one side of my head I have a Porsche (the Cochlear implant) and on the other side of my head is a bicycle (the hearing aid). The bicycle (or hearing aid) will eventually break down because the hearing loss will worsen to the point of the hearing aid being no help.*

*I'm 34 years old, so I have a career ahead of me and lots of things that I want to do. I am trying to find solutions and am interested to hear what other people's experiences are.*

Respondents then described the situation in a range of countries : Canada, Finland, USA, Finland, Slovenia, Turkey, Germany, UK:

### Canada

*The question about it being accessible for bilateral really depends where you live in Canada. Each province has the funding and some provinces do them and some provinces do not. I live in Manitoba, of course the children have two and there's the odd adult who is getting two now. We are in the process of advocating for more funding so I am told if the funding was there they could do more bilateral, so we hope we will be able to get more with two. Right now we are working on this Spend to Save programme on the national level and every province is different, it is a challenge but we're working at trying to get more in Canada.*

*In my case, I was told about five years ago by the ENT who is a surgeon that, because more than 20 years have gone by since I got my first implant that I would not be a candidate for a second one.*

### United States

*I live in South Carolina and bilateral is widely available. I, in my evaluation, I qualified in both ears. And I got my first one done four weeks later, and in about two months, I was hearing so much better with my CI and I was having trouble integrating, that hearing aid and the cochlear implant, so I decided to go ahead and get*

*the other one done. So, there's four months between my first one and my second one. And I paid my out of pocket for the year on my insurance and insurance covered both of them. So, it was very easy I know a lot of countries are not letting it, but here in America it's considered a standard of care. If you are deaf enough to qualify, it is considered a standard of care because it makes your life experience so much better*

Finland

*I am a bilateral cochlear implant user, so I live in Finland, where cochlear implants and bilateral is possible for adults but it is still dependant on your age. So if you are working age, like I am, then you can get bilateral. If you are retired or going that way, then it becomes increasingly difficult or impossible. I've had my implant for about ten years and I was implanted two years apart - which is quite a short interval for the time.*

He then commented on the issues of differing provision in differing countries:

*..... because I'm British but I live in Finland, I can get the implants in Finland. ... what will happen if I decide to move back to the UK later in life? Will I be supported? And no-one will tell me.*

*quite a lot of us that are not in the countries we started off in, and I believe cochlear implants can make it possible for us to move around, work around, be international, so we need to be prepared for that kind of migration in the future.*

Another participant had the experience of comparing different provision and the impact of differing state health care insurances:

*I'm from the Netherlands, I'm almost daily in Germany and I speak regularly to audiologist over there. She was working with children and cochlear implants and she was so surprised that insurance or Government is not covering for a second cochlear implant in our country, and then we got to talk about how much you pay for healthcare insurance. I learnt that they pay a lot more in Germany and not even double but even a lot more than that. So, yeah, it's not only about what Governments but also about how much you pay for insurance or how much you can pay yourself.*

Slovenia

*I have two cochlear implants. I can say I'm really lucky because of that because in Slovenia cochlear implants are covered completely from insurance system, also for two implants and also for adults, it's more your decision if you want to have one or two.*

### **Making the decision**

For one adult, having become deaf as an adult she was initially not wanting a second implant:

*So, when I remember my audiologist wants to stimulate me to decide for the second one because I was so, so OK, I don't know if I want the second one, I hear fine with just one. But after that, when I got the second one I saw what I missed and hearing with two implants is completely different in fact that just one. And also I sometimes in the beginning when I got first implant I also using hearing aid, but that was not for me was not OK. I was very unhappy, so after two implants I feel so, so normal. I just don't know in fact that I am deaf. And I forget on my cochlear implants and everything for me is just normal.*

But this had taken time for her to adjust, which is common:

*I got the second implant five years after first implant and it is a different - I don't know, quality of sound, my left, my first side is better than the second side. I can now compare to be with one, with left, with right, with both and this is really interesting*

## **Benefits of bilateral CI**

*I would just like to say that bilateral, once the two start working together, it is amazing the difference that you hear bilaterally versus unilaterally. When you talk about when the binaural switch turns on and you get sounds and stuff it is in the real world rather than come from inside your head. I hear so much better in noise, music is so much better.*

For several in this group, music had been a huge part of rehabilitation and important to their quality of life:

*My audiologist, I got a great one, they told me you have to work at it, your brain has to figure it out. So I picked up speech very quickly and all my rehab went into getting music back and I would play scales, just trying to force my brain into hearing stuff and it's amazing that your brain adapts to this new... displaced, completely foreign input, and it figures out ways that regain a sense of pitch and so now I am four years into it, I play guitar. I am back playing my friends and having fun with it. I listen to music all the time. It sounds a little different than my memories of it but it's so much better than it was when FIRST turned on. I feel like it is an extreme bonus to me at this point. And bilaterally is so much better for music than unilateral. You get that big sense of sound, bilaterally. I feel like I am back hard of hearing when I just use one at a time.*

*I'm with K on music. Initially for me music sounded dreadful. I play piano badly every day and it has got much better over time. Just hearing and understanding music.*

*And about music, yes, I enjoy music. I am not playing any instrument. I am not singing, But I like to dance.*

Several participants commented that when eyes are affected, then optimal hearing is even more important:

*My eyes are getting worse and worse, .....so when you are losing more sight it's getting insecure and not being able to see, but not to be able to see how far something is away from you, or to get it sharp or to see what it is. It is another thing. So. and those two together and I know there are a lot of deafblind people and how they cope but when you are starting to recognise your eyes are getting worse, then it is pretty frightening again, I must say.*

Another CI user had participated in a research project on audio-visual integration and how much it contributes to our understanding of things that going on around us.

*So you are absolutely correct that if you start, when you lose your ears, your vision takes over and you start interpreting what you see and your auditory cortex, so it is actually adding to your auditory experience, even though you are taking it in through your eyes. If you are hard of hearing and you are dependant on your eyes and you start to lose your vision, that really cuts into what you are getting through your auditory system.*

The participants were united in their support for bilateral CI from their personal experiences:

*I just think we spend too much time focussing on asking unilateral users, do you want to have two implants, rather than asking bilateral users would you like to go back to being unilateral? The bilateral users are the ones who have the experiences of using the devices and I don't know about anybody else here but according to the health systems we do not need a second ear. I can tell you I would not sell my second ear for even 1 billion euros. It make that much difference to my life. to have two ears.*

*I agree 100% with that. Through some advocacy stuff I meet a lot of people and all the ones that are on the fence about going bilateral and they wait years and years to do it, and then they finally break through and get it, and they are all just so upset that they didn't do it a decade before. I have never met a bilateral user that regretted going bilateral, even if they had residual hearing in the other ear, the balance and fullness of sound that you get with two ears working pretty much the same is just - I'm with you, I wouldn't sell my second ear for anything!*

### **Convincing funders : the impact on working**

There was discussion about the role of binaural hearing in the work place to enable people to reach their potential :

*What is the real accessibility for you - to hear with two of your ears. And also in the workplace because you can work as 100% person. I think that this is quite logical.*

And also to be safe in the workplace, and more effective which has financial benefits:

*One thing that directly relates to the money end of it is I do machine repair in fabrication shops and before I got my implants I was at a point where I could not work in some shops because I could not communicate. You have to be aware of your surroundings so you don't get hurt. And I was to the point where I could not work in the shops safely and effectively. So I got my first implant and I could understand speech and stuff so much better, but it still didn't give me any spatial awareness whatsoever. Everything sounded like it was coming from right inside the back of my head. When I got my second implant, about six months later, I could tell the moment that the hearing was pitched on in my brain - it was just after a mapping session and I got home. I got out of the truck and for the first time with my cochlear implant I could hear stuff and it sounded like it was out where it was supposed to be. I heard the chickens clucking and the truck on the highway sounded where it was supposed to be. From that point on, I would go back in the shops and feel so much more confident, you know about not getting run over by a forklift or a machine hitting you or communicating with people running the equipment. if you are looking at it from a monetary standpoint I am able to go back into the shops and be an effective part of the system, and it helped my finances out because I'm back to doing what I was doing before I lost my hearing that bad.*

*The tax reasoning is one of my favourite points to bring up for sure*

A discussion followed about the impact on employability and hence the ability to pay tax and contribute. In Finland, bilateral implants are funded in adults if you are working age. There was debate about whether the price of CI would come down if more people received two and hence more were sold.

Cost could be an important factor for those considering a second CI: .

*It is an important factor, especially for those who need to pay out of pocket, whether it is for the surgery itself or for the after care at some point in their life. But it's interesting to see and to talk about these issues as well from a cost perspective. Health insurance and funding around the world are struggling these days.*

Unilateral Cochlear implants in adults have been shown to be cost-effective and one argument was put that the savings could fund second CI. Further discussion was had about the Spend2 Save argument and that funders of health care need evidence on which to base their funding and that with regard to bilateral CI there was little.

*We are always competing with other technologies and we can't get our information and data together into the relative benefit. It is very hard to compete with other technologies that are also asking for funding, so we have to show not just the qualitative benefits but the quantitative benefits and that is very difficult.*

### **Equity of provision:**

The point was strongly made about equity of provision and societal negativity and expectations of people as they get older. It was considered that there was no equity in children receiving bilateral implants while adults did not. For example:

*I remember that when I had my first cochlear implant, that was a waiting list, and the doctor said to me cochlear implants are for children first. I was at that time 46 years old. I was in a job. I had three daughters. I was, oh, my God, what will happen with me? If I am not able to take care for my family - if I am not able to take care of my children, if I am deaf - what will be with my work? And nobody, nobody thinks about that, and I was completely down. I understand, yes, of course it is important the children get cochlear implants quickly and early but also I am important.*

*And it's not who is more important. We, all of us, are equal line, all of us are important and I think that we need to start to speak because we are the persons who are paying taxes. In Slovenia we can get two implants because our audiologists fights that fight, in fact... we have some very strong audiologists and they worked very hard in the past.*

*I'm an occupational therapist by profession and sometimes I am thinking, oh, if you are without two legs they will give you just one leg or what? Or they will give you just one arm, or they change you, or maybe help you with just one eye or something. I really don't understand that system*

A surgeon participant brought up a question he would like to ask in his quest for funding for bilaterals for adults. He pointed out that the Quality of Life assessments often had little to do with hearing and was keen to hear from users about the impact of a second implant:

*What, in your lived experience, what are the factors that bilateral implant allowed you to do? In your lived experience of bilateral implants what do they allow you to do that you couldn't before? And you can say about paying taxes. You can say you can do the job with one implant. What actually could you do that you couldn't do with one implant that might have a some kind of economic benefit, some economic spin we could try and explore?*

Wendy concluded by saying how these real stories are really important and how much they had learnt from the open responses to their questionnaire on why people chose a second implant, and why not. She supported going ahead with the question above.

Finally, Kathryn thanked all for coming and urged them to join CIICA if they hadn't already – and to join the next Conversation when we follow this popular topic.

Following the conversation, Brian Lamb sent a new reference which may be helpful: Gatto, A., Tofanelli, M., Valentinuz, G. *et al.* Cochlear implant cost analysis in adults: a European narrative review. *Eur Arch Otorhinolaryngol* **281**, 4455–4471 (2024). <https://doi.org/10.1007/s00405-024-08591-3>

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