

Examples of successful global advocacy taken from our survey

Convincing the Minister of Health to reimburse cochlear implants.

Euro-ciu and AGUAV videos translated and spread all over Europe. AGUAV project in Schools Meetings - sharing information between professionals, users and industry

In NZ, the Hear Us campaign, where health professionals, researchers and users came together for an awareness campaign and email campaign to MP's asking for increased funding for CI.

In Portugal the implementation of UNHS was possible because of a very persistent and intensive advocacy work from a steering group of professionals, long before the National Health Department recommended it (which happened only in 2015).

In the US, young people had not been provided information/support re: their legal rights after high school graduation. Educational audiologists and TODs successfully modified the format of special education plans to include a specific category regarding the knowledge and skills needed to protect their rights in higher education and the workplace.

In 2018, we started a campaign with a clear and concise intention to influence policies in Uganda on Hearing technologies. We used the strategy of commemorating the world hearing day in the Country. With the WHO facts sheets and local data, we educated the government and the public on the challenges of Hearing loss and its impact not only on individuals but on the entire family, community, and national level; and the opportunities that technology brings to us to treat and manage hearing loss. As a result, the government of Uganda has since waived all import taxes and VAT on all Hearing technologies entering the country. And the government through the ministry of Health has embraced commemorating WHD in Uganda.

The newest one in Romania, the children with special needs, so with CI, too, have insured places in mainstream schools after 8th grade. In Romania the bilateral CI is financially supported by National Health Insurance House as a result of common actions of ONGs in 2017, 2018.

Supporting the change in CI criteria with NICE

CISIC rules a FB account with 10,000 followers from everywhere to witness and advocate
Our good example is organizing meetings with people in smaller towns by CI users in order to broaden knowledge about hearing implants.

UK had good and effective work of CI advocacy group achieving change in CI criteria. Collaboration between users, manufacturers and professionals in Europe brought good results and improved standards. Internationally, such collaboration happens actively at ITU where users, manufacturers and hearing care professionals are involved in development of standards

In the US, advocates have increased reimbursement for tele-audiology and therapy
Yes, our movement #surdosqueouvem in Brazil. It's made by real users, directed by a CI user and co-directed by a CI surgeon.

We find patient information materials are excellent at empowering readers to go and ask their professionals about options that might be suitable for them. Branding from a trusted source helps their professionals know that this is a recognised option for their patient even if they have no prior expertise of experience in the area.

changing guidelines (NICE); clear mask work during COVID 19; changing service delivery (eg Denmark - access to AVT)

Yes, it was not on CI but on language learning of deaf children in the state of West Bengal, India. The Persons with Disabilities Act 1995 had a provision for deaf children to study through one language. It was not practiced in all the states uniformly. We, as a parents group advocated on the issue, submitted a memorandum, filed a PIL -Public Interest Litigation against the state government, undertook lobbying and advocacy with the education department; finally, the department acceded to our demand and we also won the case and thus single language option for children with deafness was established in West Bengal.

The Advocacy campaign by AARP to influence policy makers to open CI accessibility for elderly adults

I have advocated myself different times, when I have met someone with a severe HL .. and some of these friends now have CI either bilaterally or they have CI unilaterally and use HA on the other ear. Also the follow up and choice of HA to cooperate with the CI has been discussed. I have also helped in the follow up and training programs with information on useful listening materials - eg free access to an online audio-library for people with HL - and this is now becoming more and more commonly known also among the professionals, because users have mentioned this possibility themselves.

In the Czech Republic it has been three years that professionals, users and industry worked hard to get better conditions for CI users (from the point of view of the period for upgrades, high financial contribution of users, etc.). If everything goes in the good direction, hopefully, from 2021 we will have 7 year upgrade period and no surcharge.

Recent changes in UK candidacy, different people from various groups, professions working together to achieve the common goal.

NZ has had numerous successful advocacy campaigns

Petition organized by advocacies about processors upgrades

organization of ci centers in France in terms of follow up, indications and professionals requested

Teenage users of cochlear implants providing workshops and presentations to parents of newly implanted children. The impact was powerful as the parents: (i) saw these young people communicate in multiple spoken languages, (ii) were advised on how to support their children in the use of the technology from someone who'd "been there", and (iii) could see what was possible.

1) Early detection for kids and adults and screening. Having resources in place BUT MAINLY Creating a clear guide AND ROUTE MAP for parents, adults and families showing step by step what to do at each moment of your life from the moment you are a possible candidate, medical referrals, contacts with the industry, surgery, post surgery, schooling, work, etc. etc. 2) Advocacy campaigning with the communication masks online for our members, but as well for medical staff that is being picked up by media, politicians, schools, hospitals, etc. around the country. 3) Hearing Loss awareness in schools, working with Safe Listening showing the danger of the decibels. the kids that do the course, talk with their friends, family, etc. raising awareness of hearing loss at long term. 4) Advocacy campaign for CI students summing up the demands from CI young students and their families, contacting their schools and universities, and writing a law proposal that is being picked up by the media, politicians, and educational councils.

to provide peer-consultancy for HOH people, provide support for CI users after surgery ...

Understanding long term benefit of initial financial investment

Triangle between AEA, EFHOH and EHIMA. HEAR IT. European Platform, EDF.

Engaging the political leaders at the local and national levels..when convinced they are quick to craft policies in support of any cause..

Collaboration in UK NICE process

Working with healthcare worker on the ground - regularly To ensure support for users, families and in the workplace. Community engagement

Cost-covering by Japanese National Health Insurance and/or welfare for the handicapped

I think advocacy works best at grass roots level - hearing the message from someone in the same position as you. Social media is the way forward

The universal neonatal screening programme

In Romania, doctors that work in CI field and users fought and obtained: universal hearing screening, bilateral implantation and also CI in single side deafness and, replacement of the processor once in 7 years.

Canada has established a Hearing Health Alliance which is developing a blueprint for a national hearing Health Strategy. The Alliance is meeting with federal and provincial governments to raise the profile of hearing loss.

NICE Criteria for cochlear implantation changed - more eligible for implantation

Newborn screening advocacy work in countries that now implement this.

consumer action group (adults) presenting signatures to Ministry of health. consumers (young & older adults) talking to Ministry advisory committee.

There was a campaign of newspaper articles which I believe kick-started Finland into providing bilateral implants.

Our new CI-criteria in Belgium (since December 2019) is the result of the joint work of professionals, companies and CI-users associations. Speaking with one voice to the decision makers is a very important issue.