

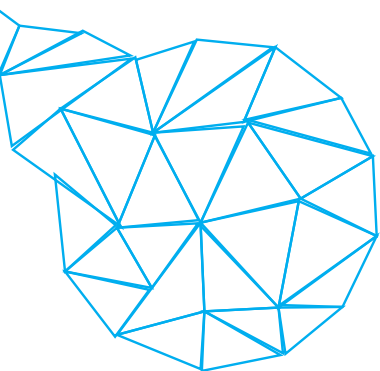


EU
ROCIU

EUROPEAN ASSOCIATION OF COCHLEAR IMPLANT USERS a.s.b.l.



ANNUAL REPORT 2022



Acknowledgements:

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EURO-CIU Annual Report 2022

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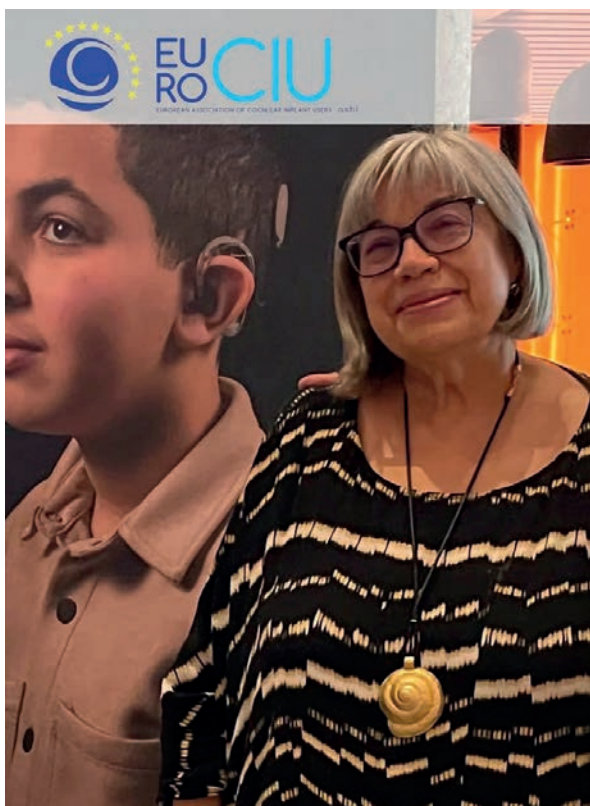
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PRESIDENT'S MESSAGE



In this report you can read about the major accomplishments of EURO-CIU during 2022 as well as 2020-2021. A more complete trajectory of events can be found in the articles in the newsletters and website brought to us by our editor Brian and webmaster Fernando.

Thanks to our member associations, we again celebrated Cochlear Implant Day, steadily increasing our visibility. We participated in World and International Congresses and Conferences relevant to cochlear implants and hearing loss. We also held our own EURO-CIU Symposium in conjunction with ONICI and OPCI in Rotterdam, The Netherlands. The huge turnout confirmed interest in updating all medical, technical, social and rehabilitation areas related to cochlear implants. For the first time ever at a EURO-CIU Symposium, half of the speakers were CI users themselves.

Regarding participation and collaboration with other entities, we are pleased to have continued with our active presence both in the Platform (EPDHD) and in EDF (European Disability Forum), thanks to Sari as delegate in this forum, and to Laia and Robert in the Work Commissions. In addition, our presence in the

European Parliament & European Commission has been productive, as evidenced by the celebration of Disability Day and the meetings with Members of the Parliament that I have made.

It is important to highlight that we have continued to work at a global level both from the WHO safe listening working group and from CIICA to give visibility and work in a network combining synergies.

EURO-CIU has never before been as active in high political and influential circles. This means that we can raise our voices so that our needs are heard. To have a free and accessible society Europe must be a place where everyone listens. Cochlear implants make it possible for deaf people to hear and listen. Now it is the national and European administrations' turn to listen to us.

The Covid-19 pandemic had a negative impact on the number of implant operations carried out. There is now a backlog coupled with tightened finances. EURO-CIU must push hard to make sure that our regions invest more in cochlear implants and live long care, rather than scaling back, so that CI candidates and users do not suffer.

On the other hand, these past years has improved accessibility to communication and new technologies help our daily life. We need to translate innovation to our devices, fitting and rehabilitation; as well as to keep working at European Parliament to implement a European Disability Card that includes everyone and gives real support and benefits to Cochlear Implant Users.

We face 2023, with the must improve our presence in social networks and to give more voice to our youth. We should also transmit our message using experiences and needs from all our members, all over Europe, to show our real diversity to face the challenges ahead.

Teresa Amat,
EURO-CIU President

WHAT ARE COCHLEAR IMPLANTS?

Cochlear implants (CI) are high-tech devices which enable profoundly and severely deaf people to hear. A CI system consists of two parts: an external processor which usually resembles a hearing aid, and a surgically implanted receiver. The external processor converts sound into signals and transmits them to the implanted receiver. These signals pass directly to electrodes in the cochlea, stimulating the auditory nerve to the brain.

Anyone who suffers from unilateral or bilateral severe or profound deafness, and gets little or no benefit from hearing aids, can potentially benefit from cochlear implants. Candidates for cochlear implantation typically have around 80 dB - 90 dB (decibels) hearing loss. The exact criteria used for implantation varies depending on the region and is not based solely on dB levels.



WHAT ARE COCHLEAR IMPLANTS?

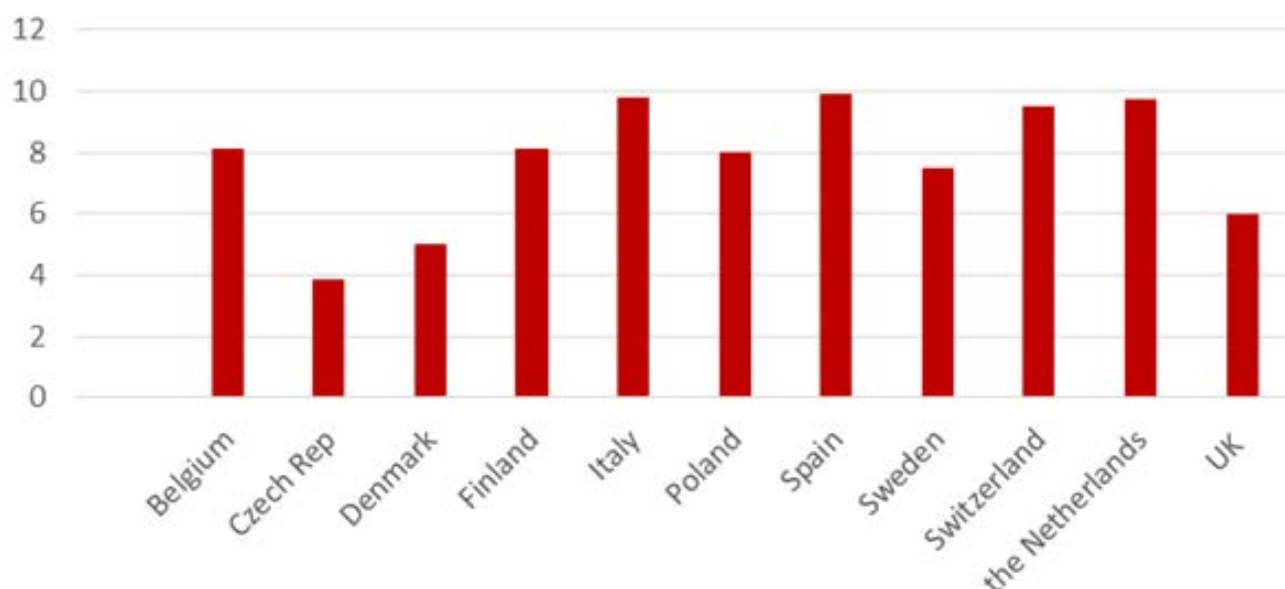
Prevalence of cochlear implants in Europe in 2017

Exact data on the prevalence of cochlear implants is difficult to collect because it is not publicly available. Therefore, these graphs only show countries where we have confidence in the data.

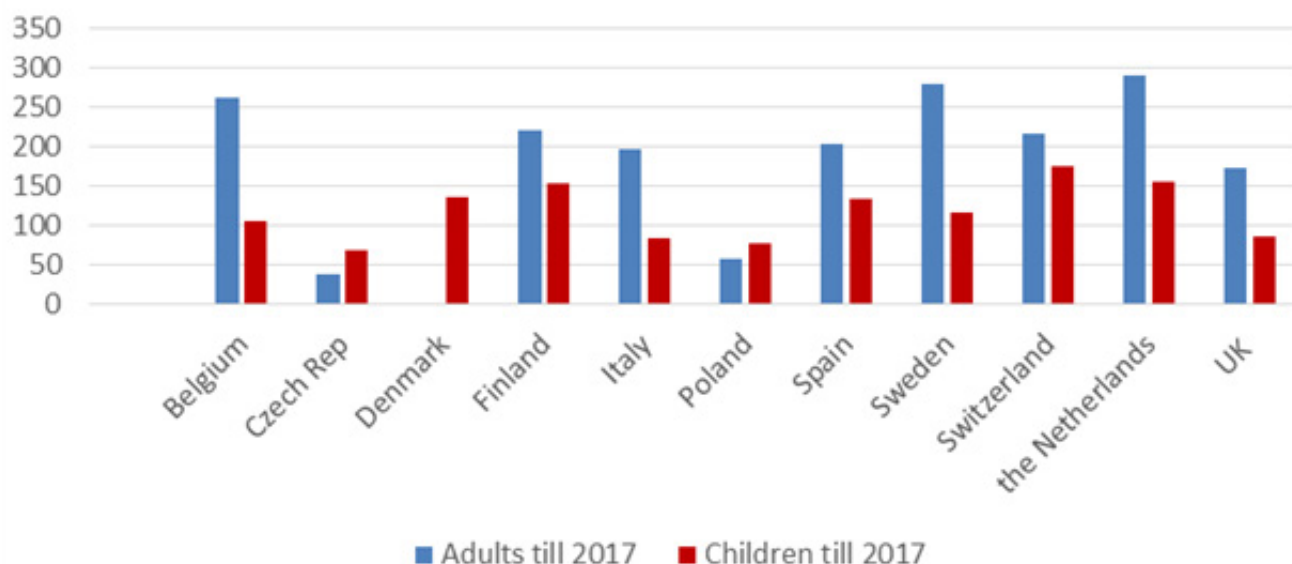
In most of Europe the number of paediatric cochlear implant operations per 10,000 new-borns falls between 8 and 10 children. These numbers correspond very well with the data from publications on the prevalence of hearing loss, indicating that 1 out of 1000 new-borns have a severe to profound bilateral hearing loss. The Czech Republic, Denmark and UK, lag behind with paediatric cochlear implantations.

The second graph compares the number of implants in children and adults up to 2017. Compared to children, there is clearly more variation and under-implantation in adults. East European countries (Poland, Czech Republic) clearly prioritise children over adults.

Number of pediatric CI's per 10000 newborns. 2017



Total number of CI-users per million inhabitants (till 31 december 2017)



EURO-CIU in brief

EURO-CIU is a non-governmental, non-profit association, established in Luxembourg in 1995. The association brings together 29 national member associations from 22 European countries. Altogether EURO-CIU represents the users of around 250,000 cochlear implants across Europe, approximately 60% of whom are adults and 40% children. Each year, around 25,000 European citizens receive cochlear implants. Globally, around 1 million cochlear implants are in use.

Our aims:

- To support cochlear implant candidates and users of all ages:
- We promote access to CI with costs covered by national healthcare systems. Cochlear implants are cost effective using any current cost benefit measure.
- CI candidacy must be based on each patient, not just on auditory thresholds. All parties involved must be fully informed so that they can give proper consent.
- All professionals supporting CI-users must have up-to-date knowledge.
- Comprehensive rehabilitation and lifetime support must be provided, together with assistive hearing technologies. Implant systems must be maintained and processors regularly renewed.



To support children:

- Encourage early detection via screening followed by early family-centred intervention.
- Identify CI candidates ideally before 9 months of age and no later than 18 months of age.
- Support binaural hearing. Sequential bilateral implants should be 3 months to 1 year apart.
- Ensuring the adequacy of educational programmes post-implant for optimal outcome.
- 30%-40% of CI users have additional needs, so support must be multidisciplinary.
- Access to inclusive, high quality, free education, face to face or online.



Raising awareness:

- We are highlighting the societal costs of untreated hearing loss.
- We advocate for hearing screening for all new-borns and adults from around age 55.
- We are increasing awareness of best CI practice amongst patients, families, health professionals, educators, policy-makers, funders and the general public. Doctors and audiologists need to recognise the potential benefits of CI to adults of all ages.
- Educate and encourage policy-makers and public health authorities to promote CI.
- Collaborate with other organizations to promote CI as the standard of care treatment within non-hearing loss disciplines.

Research:

- Encourage and support research on all aspects of CI for children and adults.
- We support an annual symposium or workshop to highlight research, clinical issues, rehabilitation, quality of life/cost effectiveness, health care policy, insurance issues, etc.

Accessibility:

- Ensuring accessibility to information with support for oral communication in all areas of life, both public and private, including induction loops, speech-to-text interpretation, captioning, connectivity and improved environmental acoustics. Products, environments, programmes and services must be accessible to all.

ACTIONS DURING COVID-19

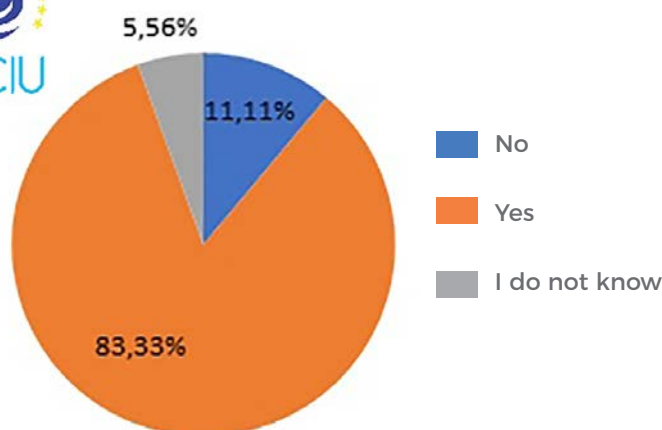
The Covid-19 pandemic significantly affected cochlear implant users. To begin with, cochlear implant operations stopped almost everywhere. CI users suffered major challenges due to face masks, inaccessible online education, and difficulties communicating when in hospital. Post-pandemic, we fear that economic cutbacks will reduce the number of operations, rehabilitations and processor upgrades being carried out.

Survey of the CI situation in Europe during the pandemic

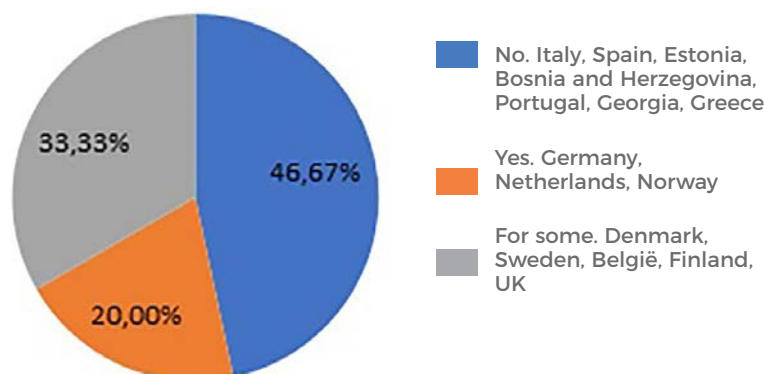
EURO-CIU surveyed its members in April 2020, to see how the pandemic was affecting CI users in Europe. Eighteen member countries replied.



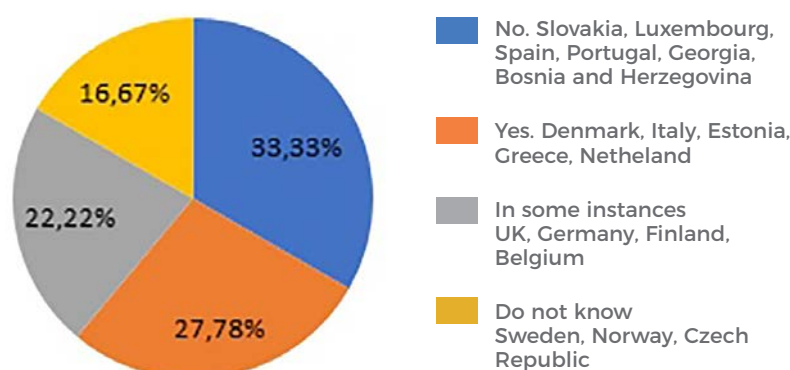
Have CI surgeries stopped?



Did they start with remote fitting to replace live-fittings?



Did they start with remote rehabilitation to replace live-rehabilitation?



Care must be taken in drawing conclusions, because there were many unknowns and uncertainties in the answers. For example, different practices were being followed in different regions and situations were changing daily.

In 83% of countries, cochlear implant operations ceased completely, except in special cases, because they were not considered urgent.

The pandemic prompted an increase in remote activation and mapping of cochlear implant processors. This should be good for CI users in the long term because it reduces the need to travel to clinics for adjustments.

The pandemic created a backlog of CI operations. Clinics must catch up as fast as possible. Delays will permanently affect the possibility for infants to acquire good speech perception.

We have seen that economic resources are being challenged post-pandemic, threatening cochlear implantation programs. We must keep reminding health services that cochlear implants are a good investment, cost effective using any current cost benefit measure.

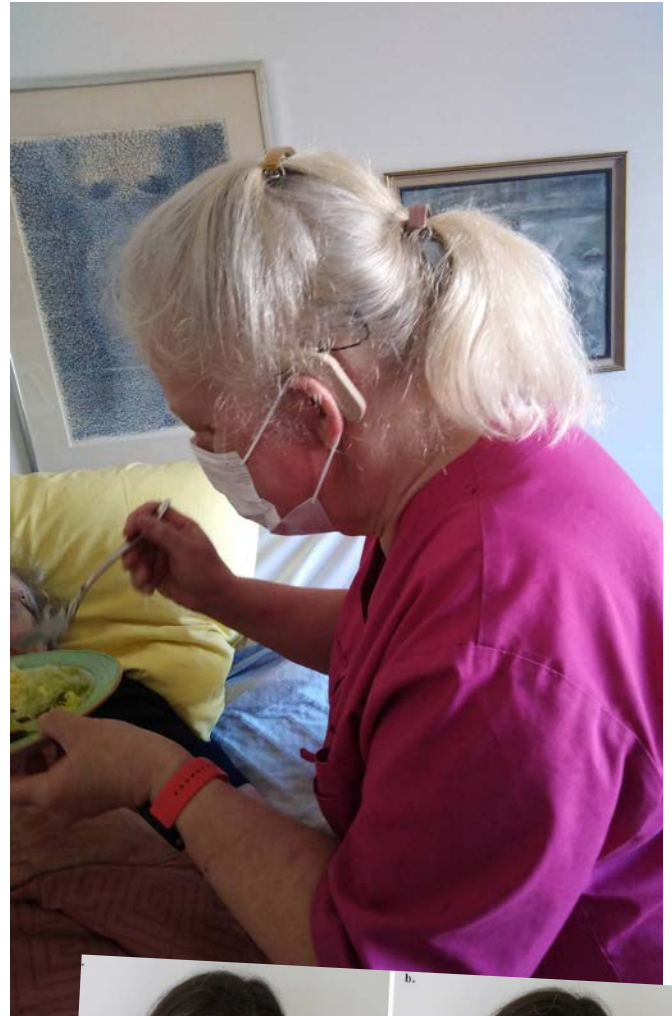
The complete Survey Report: <http://eurociu.eu/covid-19-documentation>

Face masks

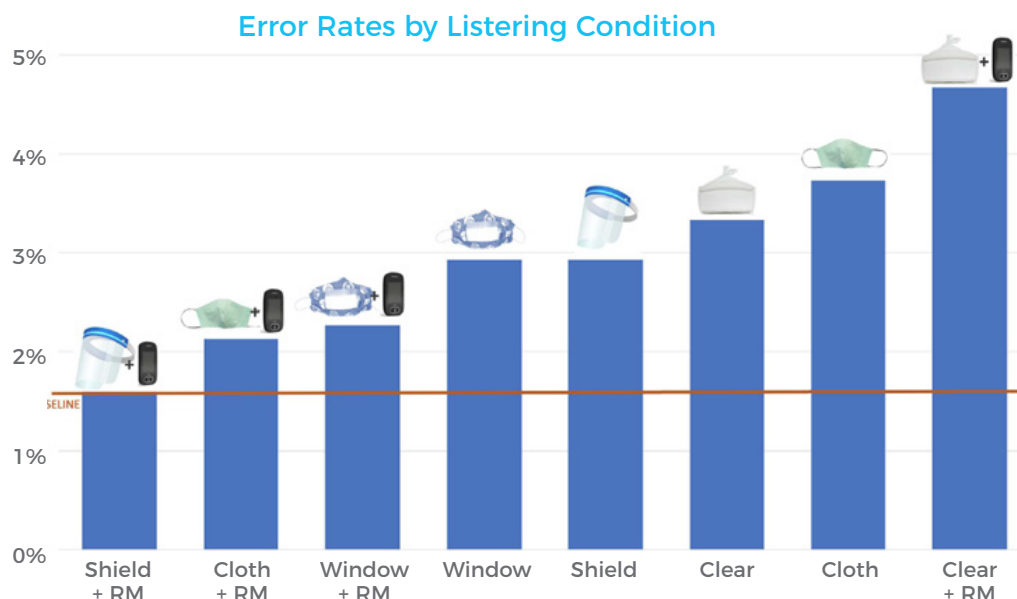
MOSA The use of protective masks seriously affects CI users. Masks and face shields inhibit both the visual and auditory aspects of communication. Typical opaque masks (cloth or medical) present an obvious visual barrier to people with a hearing loss who need to lip read. Besides shielding the face, materials also cause acoustic degradation, particularly in the all-important high frequencies. Speech quality degradation, combined with poor room acoustics and the absence of visual cues can render speech close to unintelligible for people with hearing loss.

Masks have been developed, for example in Spain and Portugal, combining layers of fabric with a transparent central acetate window. Our member, Federation AICE, has manufactured and distributed more than 50,000 units of their “+ Com” masks.

Different operating environments require different levels of certification. The challenge is to create certified hygienic transparent masks for all situations which do not fog, reflect or cause acoustic degradation. EURO-CIU is working with ANEC, <https://www.anec.eu/>, the European consumer voice in standardisation, to create a European standard all countries could abide to. A European regulation is necessary to clarify the conditions and certification for this type of mask.



Percentage of speech perception error as measured by the CNC test in nine variations of face covering conditions, including the baseline condition of no face covering and no remote microphone (RM) represented by the orange horizontal reference line. (Rudge et al, Moog Center, 2020)



For more information, see our website. <https://eurociu.eu/>

Euro-ciu demands accessible online education

EURO-CIU is working to ensure that regulations about accessible education include online education. During COVID-19, thousands of students with cochlear implants have been left behind because schools and teachers failed to make online classes accessible.

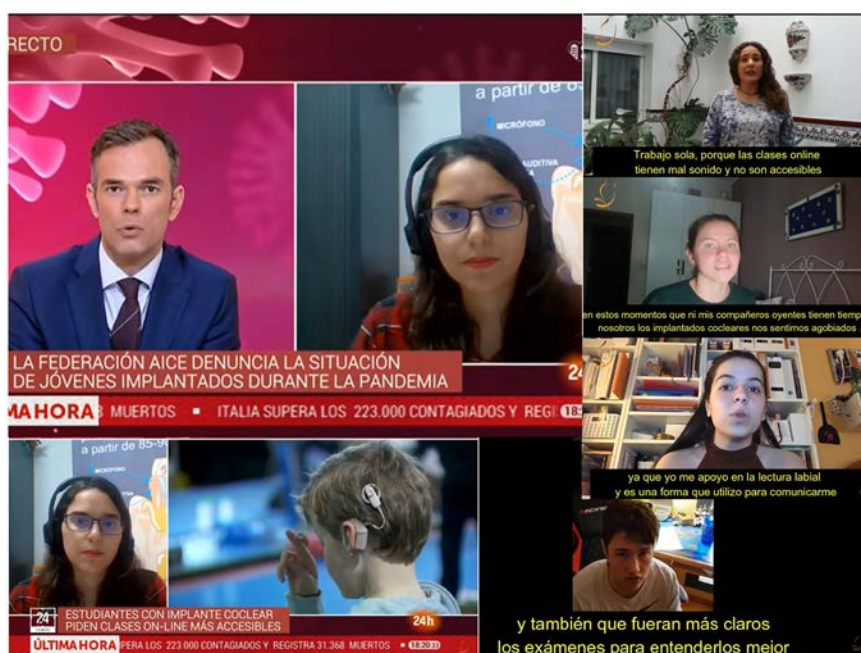
Students face **many obstacles which prevent lip-reading and understanding**, including inferior microphones, cameras, lighting, internet connections, and video synchronisation.

Professionals are rarely on hand to caption classes. Although popular video calling platforms offer automatic captions, they do so only in English and with poor accuracy.

Meanwhile, online, students are being denied their right to more time in which to finish their exams.

Laia Zamora, of EURO-CIU's member AICE Federation, went on public national television to defend the fundamental rights of deaf people and to demand immediate tangible solutions and proposals for all students with hearing loss, including cochlear implant users, by the Ministry of Education, Departments of Education of the Autonomous Communities, Universities, Educational Centres, Institutes and Schools.

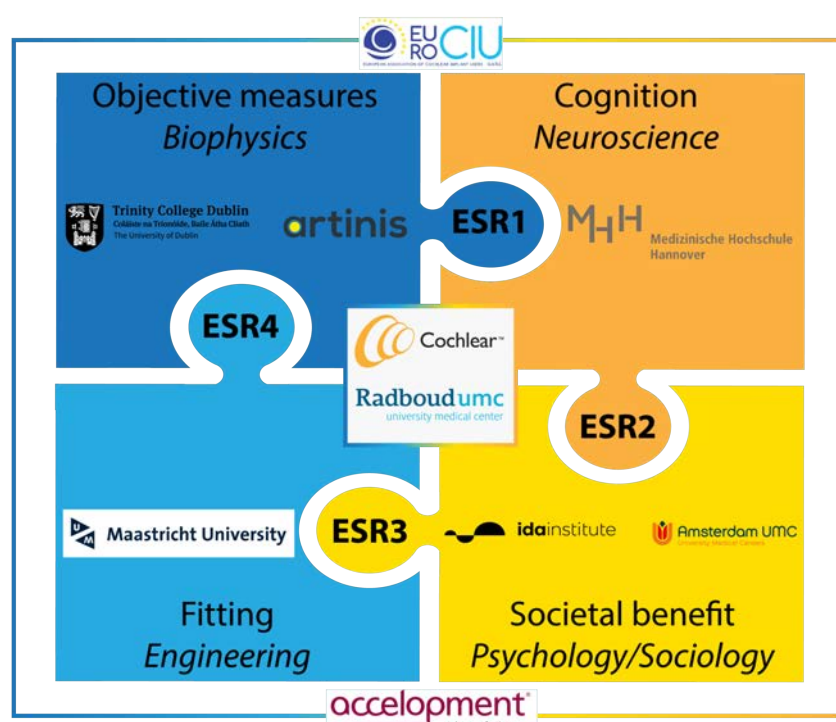
AICE Federation has gathered the claims of several students in a video, presenting the main barriers met by cochlear implant users in online classes. Check it out here (Spanish, with Spanish captions): <https://youtu.be/16ipO2f9UTo>



COLLABORATIONS AND PROJECTS



MOSAICS European Industrial Doctorate project



"EURO-CIU's contribution was an important milestone for us. Gathering knowledge and experience from diverse points of view, widens our vision on the CI field" said ESR Ignacio Calderon De Palma.

Enrico Migliorini introduced his AuDiET study, the centrepiece of his PhD candidate programme, at EURO-CIU's Symposium in Rotterdam. 14 "I could not have asked for a better audience to present to than the one at the EURO-CIU symposium. Being there reminded me of the reason why I started my PhD journey: your warm welcome, the numerous questions and the shows of interest made me feel deeply humbled at the thought of being able to do a part in helping the CI community" enthused Enrico Migliorini.



To follow MOSAICS: @MOSAICS_2020 <https://www.mosaics-eid.eu/>

CONSENSUS on a minimum standard of care for treating adult hearing loss with ci



The world's first international consensus on CI treatment for adults living with severe to profound sensorineural hearing loss was published on August 27, 2020 in JAMA Otolaryngology. [Buchman CA et al. Unilateral Cochlear Implants for Bilateral Severe, Profound, or Moderate Sloping to Profound Sensorineural Hearing Loss. JAMA Otolaryngology 2020. Epub ahead of Print.]

The paper was authored by 31 hearing experts on cochlear implant treatment, assisted by a Consumer and Professional Advocacy Committee (CAPAC) of international cochlear implant user and professional advocacy organisations, to ensure the voice of users was heard throughout the process. The consensus paper includes 20 statements covering seven categories for adults with severe to profound bilateral hearing loss. Each statement was agreed upon by the panel members after consultation with the CAPAC, which included seven organisations representing cochlear implant users and professional societies, including EURO-CIU.

The consensus statements represent an important milestone because the knowledge and guidance they foster provides guidance to clinicians that will better define referral, treatment and aftercare pathways for patients and promote best clinical practice. It will provide patients and their caregivers with reference points for the care they should be receiving, helping them with questions to ask when they are not getting the information they need.

www.eurociu.eu

<https://eurociu.eu/media/files/2020-consensus-ADULT-HEARING.pdf>

www.jamanetwork.com/journals/jamaotolaryngology

www.adultheating.com



Coinciding with the launch of the consensus statements, EURO-CIU was interviewed. Find the videos on EURO-CIU's YouTube channel or on the Adult Hearing website.



Consensus Statement 1:

Awareness of cochlear implants among primary and hearing healthcare providers is inadequate, leading to under-identification of eligible candidates. Clearer referral and candidacy pathways would help increase access to cochlear implants.



Consensus Statement 2:

Detection of hearing loss in adults is important; pure tone audiometry screening methods are considered the most effective. The addition of a questionnaire or interview to the screening can improve the detection of sensorineural hearing loss.



Consensus Statement 3:

Preferred aided speech recognition tests for cochlear implant candidacy in adults include monosyllabic word tests and sentence tests, conducted in quiet and noise. Further standardisation of speech recognition tests is needed to facilitate comparison of outcomes across studies and countries.



Consensus Statement 4:

Age alone should not be a limiting factor to cochlear implant candidacy, as positive speech recognition and quality of life outcomes are experienced by older adults as well as younger adults.



Consensus Statement 5:

Both curved (perimodiolar) and straight electrodes are clinically effective for cochlear implantation, with a low rate of complications.



Consensus Statement 6:

When possible, hearing preservation surgery can be beneficial in individuals with substantial residual hearing.

Statement 7:

Cochlear implants significantly improve speech recognition in both quiet and moderate noise in adults with bilateral severe, profound, or moderate sloping to profound sensorineural hearing loss; these gains in speech recognition are likely to remain stable over time.

Statement 8:

Clinical Effectiveness of CIs Both word and sentence recognition tests should be used to evaluate speech recognition performance following cochlear implantation.

Statement 9:

Cochlear implants significantly improve overall and hearing-specific quality of life in adults with bilateral

severe, profound, or moderate sloping to profound sensorineural hearing loss.

Statement 10:

Adults who are eligible for cochlear implants should receive the implant as soon as possible to maximize post-implantation speech recognition.

Statement 11:

Where appropriate, individuals should use hearing aids with their cochlear implant in order to achieve bilateral benefits and the best possible speech recognition and quality of life outcomes.

Statement 12:

Many factors impact cochlear implant outcomes; further research is needed to understand the magnitude of the effects.

Statement 13:

Long durations of unaided hearing loss do not rule out potential benefit of cochlear implants: individuals who receive an implant in an ear that was previously unaided for more than 15 years have been shown to experience improvements in speech recognition.

Statement 14:

Adults who have undergone cochlear implantation should receive programming sessions, as needed, to optimise outcomes.

Statement 15:

Adults with hearing loss can be substantially affected by social isolation, loneliness, and depression; evidence suggests that treatment with cochlear implants can lead to improvement in these aspects of well-being and mental health. Longitudinal studies are needed to obtain further knowledge in this area.

Statement 16:

There is an association between age-related hearing loss and cognitive/memory impairment.

Statement 17:

Further research is required to confirm the nature of cognitive impairment in individuals with hearing loss, and its potential reversibility with treatment.

Statement 18:

The use of cochlear implants may improve cognition in older adults with bilateral severe to profound sensorineural hearing loss.

Statement 19:

Hearing loss is not a symptom of dementia; however, treatment of hearing loss may reduce the risk of dementia.

Statement 20:

Unilateral cochlear implantation in adults is cost-effective when compared with no implant or no intervention at all and is associated with increased employment and income.

CIICA, cochlear implant international community of action



This illustrates why it is so important to strengthen the advocacy platform of user organisations, so there is not only focus on surgery and audiology, but also on client-centred rehabilitation, quality of life and the well-being of CI-users.

Coinciding with the launch of the consensus statements, Leo De Raeve, EURO-CIU's scientific advisor and Robert Mandara, EURO-CIU Vice-President, were interviewed. The videos can be viewed on EURO-CIU's YouTube channel or on the Adult Hearing website.

In December 2019, EURO-CIU were part of an exciting meeting of advocacy groups, professionals and representatives of the four CI companies in Geneva, considering the International Consensus Statements for Adult Cochlear Implantation and how global advocacy for CI could be taken forward.

Brian Lamb and Sue Archbold were asked to carry out a global consultation to identify the barriers to CI and how we could best increase global access to CI. This consultation took part in the first half of 2020, and resulted in the recommendation that a Community of Action for CI was formed. CIICA is a global community which brings together organisations and individuals who share the vision and goal of increasing access to CI and lifelong support.



A digital platform to act as the hub was seen as key to this development and planning for CIICA began towards the end of 2020. EURO-CIU are delighted to be Founding Members of CIICA. Our President Teresa Amat is on the Steering Group, and our Vice President, Robert Mandara is a full member and on the website/communication group. CIICA was launched on International CI day, 25th February 2021.

Since launch, CIICA has hosted many online CIICA Live and CIICA Conversation events, in which our Vice-Presidents have made presentations and been very active. Young adult CI users are supported and encouraged into advocacy work through their own CIICA Conversations.

EURO-CIU collaborates closely with CIICA and has released joint briefing documents.

To see events, resources and to join, see www.ciicanet.org



GOAL: To raise awareness of the huge impact of hearing loss in both children and adults, and to build political commitment to improving hearing care, with greater access to hearing technologies, including cochlear implants.

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VISIBILITY

We participate in a great many events, both presenting and asking questions from the audience. The following are examples of how we have been raising the visibility of cochlear implants.

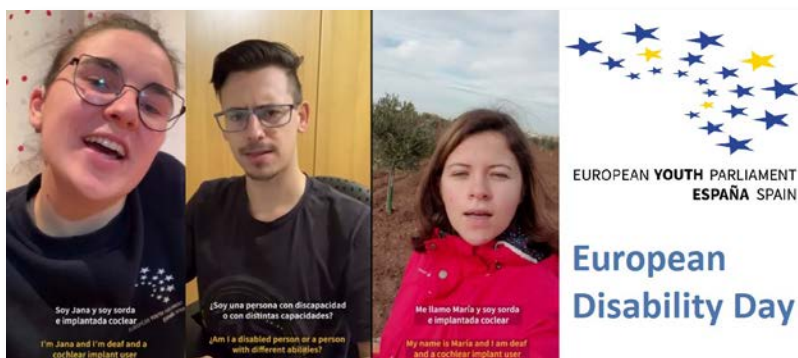
International / European Day of Persons with Disabilities

The European Day of Persons with Disabilities conference was held online on 1st - 2nd December on 2021 and on 2022 in Brussels. EURO-CIU has participated in this event organized by the European Commission for the last eight years. Our President, Teresa Amat, and EDF representative, Sari Hirvonen Skarbö attended the meeting. They used the opportunity to highlight the need for a more accessible society for all disabilities, with emphasis on cochlear implant users.

Politicians, high-level experts and self-advocates attend the conference to discuss the challenges, solutions and projects for improving policies dedicated to persons with disabilities.

The conference is a great opportunity to explain our specific needs, raise awareness and have input into policies relating to deafness and communication barriers.

Some of national members, like Federación AICE (from Spain), in conjunction with the European Youth Parliament Spain, launched a video showing several young people with cochlear implants, from different European countries and following different professions. Participants answer the question: Am I a person with a disability or a person with diverse abilities? CI users are made visible, putting them at the centre, normalizing their lives and virtues.



The video is accessible with subtitles in both Spanish and English.

<https://www.youtube.com/watch?v=h97imlYqLwY>

During the pandemic people with disabilities have been isolated and deaf people have been deprived of communication because opaque masks prevent lip-reading. The collaboration with European Youth Parliament Spain highlights the challenges with the "Listen to the difference, implement equality" campaign. All society must be involved, since equality, tolerance and respect is everyone's business.



25th February Cochlear Implant Day

25th February, international Cochlear Implant day is an opportunity to celebrate how cochlear implants have transformed lives, and also to communicate the need for more comprehensive neonatal and adult hearing screening, prompt provision of hearing technologies, accessibility and appropriate rehabilitation. Globally there are still great inequalities, particularly with regard to older persons, bilateral provision and processor renewals. Only one in 20 adults who could benefit currently has a cochlear implant.

CI Day grows and becomes more widespread every year. All kinds of activities are arranged locally, including courses, conferences, visits, sports events and television appearances. CI users, their families, medical professionals and policy makers are all involved.

For example, **to celebrate International Cochlear Implant Day on 25th February 2020, our member associations made their voices heard loud and clear with a campaign entitled I want to hear. Can you hear me? Accompanying videos showed people who are fully integrated into school and work life, thanks to their cochlear implants.**



Countries must invest in the prevention and treatment of hearing loss, to ensure the best possible hearing functionality, by providing prompt access to the best technology and state-of-the-art hearing rehabilitation. **Investing saves money. The cost of NOT providing hearing technologies has been shown to far exceed the cost of providing them.**



www.eurociu.eu @eurociu

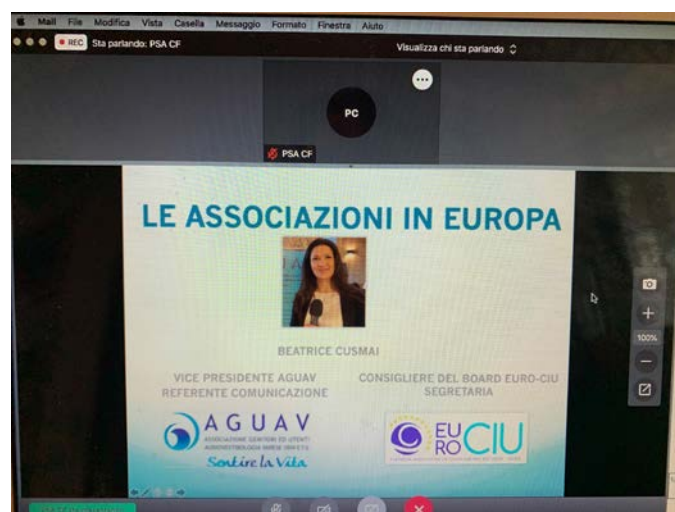


The G.O.O.D. (Global overview on deafness)

An online congress, "The G.O.O.D. 2020" was organised on 11th-12th December 2020 by AGUAV and FAV, in Italy. This celebrated the 10th Anniversary of the scientific director Doctor Eliana Cristofari who has led the Audiovestibology Department of Varese since 1st December 2010.

Over 500 participants celebrated this decade of success together with more than 100 speakers from all over Europe, including audiologists, otolaryngologists, audiometry and hearing aid technicians, speech therapists, paediatricians, geriatricians, and infant neuropsychiatrists. The aim was to take a snapshot of how deaf and hard of hearing people are treated in Europe, presenting research from the scientific world and also from trade and patients' associations.

EURO-CIU was represented by our President Teresa Amat who emphasized that EURO-CIU's role is to underline the needs of CI users; our Secretary Beatrice Cusmai, Vice-President from AGUAV explained the importance of the network among European Associations, and how useful is the synergy and cooperation to reach common goals, supported by many examples.



SEORL-CCC Spanish National Congress

EURO-CIU was present at the 73rd SEORL-CCC Spanish National Congress, held on 13th – 15th October 2022. The congress was organised by the Spanish Society of Otorhinolaryngology Head and Neck Surgery, under the presidency of Dr. Del Rosarios and Dr. Ramos Macías. National and international scientists gathered in the Congress Palace, at Las Palmas, Gran Canaria.

President Teresa Amat and the 2nd Vice President Beatrice Cusmai at the EURO-CIU stand, giving out information about the association and the advocate actions held also during the pandemic.



Nordic Adult CI Action Group



On 23rd January 2020, fourteen representatives of CI associations from the five Nordic countries took part in the first Nordic Advocacy Meeting in Copenhagen, led by Sue Archbold and Brian Lamb. This was followed up with regular online meetings through 2021 and 2022.

The Nordic Adult CI Action Group of CI patient associations from the five Nordic countries, including representation from EURO-CIU and CIICA, have jointly produced the Nordic Declaration on Adult Cochlear Implantation in order to address this. The aim is to increase access to the provision of CI and lifelong services in the Nordic countries.

The Declaration was launched across the Nordic countries on World Hearing Day, focussing on adults with severe to profound hearing loss.

The group have worked quickly to achieve this agreed document which we look forward to using for further advocacy work. Download it from:

<https://ciicanet.org/2022/03/02/nordic-declaration-on-adult-cochlear-implantation/>

On average, across the Nordic countries, 9 in 10 who could benefit from cochlear implants, have not been implanted.



European Disability Forum (EDF)

“Nothing about us without us.”

The European Disability Forum is an independent NGO which brings together representative organisations of 100 million European persons with disabilities, run by people with disabilities and their families.

EURO-CIU supports EDF's campaigns in the European Union to achieve laws, regulations & directives that help persons with disabilities, especially users of cochlear implants.

Accessibility is a profound political and human rights issue. The European Union has a unique opportunity to be a role model of accessibility and universal design by making all of its institutions fully accessible for everyone.



EDF has published the Toolkit of EDF's recommendations for equal access and choice of electronic communications services, the European Electronic Communications Code (EECC or the Code). This EU Directive called on governments to adapt their national laws to comply with the code by 21st December 2020. One goal is to ensure the provision of good quality, affordable, publicly available and accessible electronic communication

services to persons with disabilities. For example, it should be possible to communicate via text message to a single European emergency number, 112, at any time.

The COVID-19 pandemic has highlighted the importance of accessible communication. CI users suddenly had to get used to a plethora of videoconference applications, contend with face masks and learn new ways of getting speech-to-text and sign language interpretation remotely.

Sari Hirvonen-Skarbö, EURO-CIU's representative to EDF, along with Robert Mandara, EURO-CIU Vice-President, participated in EDF's online seminar on 2nd and 3rd December 2021. Prizes were awarded to Europe's most accessible cities. One important topic was about how artificial intelligence (AI) is being used by companies to screen candidates for jobs, and that this can unfairly discriminate against people with disabilities.



Sari Hirvonen-Skarbö was elected to the board of EDF in June 2022

Together, EURO-CIU and EDF are a strong, united voice for persons with disabilities in Europe.

For more information see:

www.edf-feph.org/

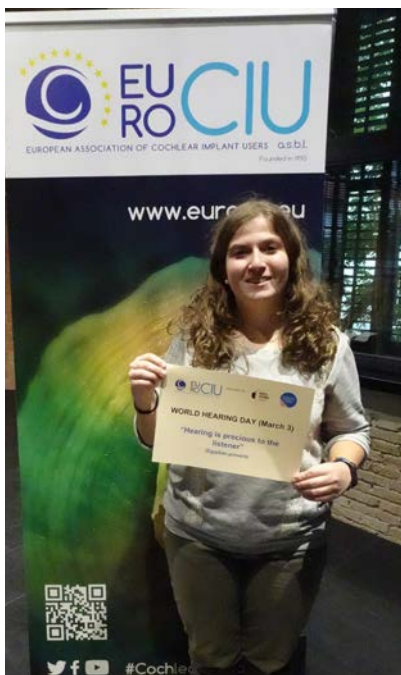
EURO-CIU IS A MEMBER OF...

World Health Organisation (WHO) and World Hearing Forum (WHF)

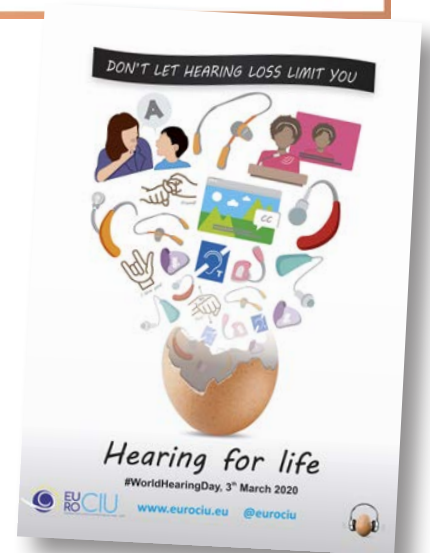


The WHO and EURO-CIU work together to prevent hearing loss and draw attention towards the anticipated rise in the number of people with it across the world. Where hearing loss is unavoidable, we raise awareness to ensure access to appropriate and affordable assistive technologies such as hearing aids and cochlear implants, and communication services like speech therapy, sign language and captioning.

In September 2019 EURO-CIU became a member of the World Hearing Forum (WHF) hosted by the World Health Organization and established in September 2018. EURO-CIU were invited to be part of the Safe Listening Working Group.



The WHF envisions a world in which no person experiences hearing loss due to preventable causes and those with hearing loss can achieve their full potential through rehabilitation, education and empowerment.



The goal of the Forum is to facilitate the implementation of the WHA 70.13 resolution and to support the WHO's advocacy actions in the field of hearing.

Objectives:

- ▶ Undertake advocacy efforts for galvanizing support and raise awareness for ear and hearing care.
- ▶ Promote networking for knowledge sharing.

The membership responsibilities are:

- ▶ Promote the work, vision, goals and objectives of the Forum.
- ▶ Actively initiate and participate in the activities, discussions and deliberations of the Forum.
- ▶ Participate in the Forum Membership Assembly.
- ▶ Participate, as appropriate, in the Forum working groups.
- ▶ Share knowledge and information with other members of the Forum.

World Hearing Forum Members are part of a vast network of like-minded stakeholders working to address and promote ear and hearing care worldwide. EURO-CIU's Board are working hard to rise to the challenge and to engage members to follow suit. Cochlear Implant Users must become leaders of the hearing movement. During the pandemic we have been participating in the WHO webinars on hearing care health. On 3rd March 2020 EURO-CIU participated in World Hearing Day 2020, with the theme "Don't let hearing loss limit you. Hearing for life!" WHO highlighted that timely and effective interventions enable people with hearing loss to achieve their full potential. It drew attention to the options available in this respect. As well as technical aids such as cochlear implants, focus was on breaking down communication barriers, rehabilitation, improving accessibility and lifelong care. Investing in hearing care is socially profitable and, perhaps surprisingly, can also delay the onset of other costly pathologies. EURO-CIU and its members organized events around Europe, contacted politicians and raised awareness online, striving to change behaviours in society with Safe Listening and Check your hearing messages.

For example, in the UK, Lilian Greenwood MP and the National Association of Deafened People (NADP) hosted a drop-in event in the Houses of Parliament. MPs and their staff could take part in a lip-reading challenge, test their hearing with the "hearWHO" app, learn about the dangers of listening to loud music, and learn communication tips. The event highlighted the need for access to hearing care and assistive technologies. MPs fully engaged in the demonstrations and responded positively.



Key messages of World Hearing Day:



At all life stages, communication and good hearing health connect us to each other, our communities, and the world.

For those who have hearing loss, appropriate and timely interventions can facilitate access to education, employment and communication.

Globally, there is lack of access to interventions to address hearing loss, such as hearing aids.

Early intervention should be made available through the health systems.

Robert made a 20 minutes' presentation about his experiences with tinnitus & CI to Cochlear's research centre's

World Hearing Day webinar. Other key note speakers included Mark Laureyns and David Stockdale, CEO of the British Tinnitus Association.



Further information: www.who.int/deafness/world-hearing-forum/en/

European Platform of Deafness, Hard of Hearing, and Deafblindness (EPDHDB)

The European Platform of Deafness, Hard of Hearing and Deafblindness (EPDHDB) was created during the General Assembly of the European Disability Forum in 2012.

The platform was formed to enhance, strengthen and cultivate a robust and enduring collaboration between eight organisations: EURO-CIU, The European Deafblind Network (EDbN), The European Deafblind Union (EDbU), The European Federation of Hard of Hearing People (EFHOH), The European Federation of Parents of Hearing Impaired Children (FEPEDA), The European Union of the Deaf (EUD), The European Union of the Deaf Youth, and The International Federation of Hard of Hearing Young People.



The purpose is to benefit all deaf people and their families, regardless of the language, communication methods or hearing instruments they use. Representatives from each organization meet a few times a year but have not met at all during the pandemic.

Further information:

info@epdhdb.eu

www.epdhdb.eu

[@EPDHDB](https://twitter.com/EPDHDB)

EURO-CIU Symposium: 11th November 2022, Rotterdam



Photos: top left - the group of organisers; top right - different languages on the screens; bottom left - delegates at the symposium; bottom right - EURO-CIU stand.

After two years of preparation by the members of OPCI and ONICI, our first post-pandemic EURO-CIU Symposium was held at the Postillion Congress Center in the heart of Rotterdam. Over 200 visitors attended, including around 45 members of EURO-CIU.

The topic "Cochlear implants now and in the future: what do we already know and what can we expect?" was explored from various angles in 14 presentations given by professionals and CI users. For the first time in the history of EURO-CIU symposia, half of the speakers were CI users.

The event was very accessible. The presentations were supported by a sign language interpreter and by speech-to-text interpreters: with four languages shown on large screens. Other languages could be accessed by scanning a QR code and viewing on a mobile device.

The breaks were used to exchange experiences and to explore the extensive information market, featuring event sponsors, CI manufacturers, affiliated hearing aid manufacturers and other organizations involved with CI users.

Feedback indicated that the Symposium was a huge success and relevant to professionals as well as CI users.

After the congress, the EURO-CIU participants, the speakers and the organization went on a city tour of Rotterdam, which was concluded with a dinner.

To get an impression of the content of the presentations, the PowerPoints of the speakers can be accessed on the EURO-CIU website.

EURO-CIU Annual General Assembly: 12th November 2022



The EURO-CIU Annual General Assembly took place in Rotterdam, immediately after the Symposium, and was opened by our President, Teresa Amat. This was our first face-to-face meeting following the Covid-19 pandemic.

Pieter Bolle (Belgium), a parent of a CI user, was elected as our new Secretary.

Teresa Amat stressed that we must continue working to achieve more collaboration between EURO-CIU and our members, so that it is a truly

reciprocal relationship with give and take. We must encourage members to go, on behalf of themselves and EURO-CIU, to European and International level events. We must also work on the problem of the lack of generational change in many of the member associations by encouraging young adult CI users into CI advocacy.

Problems aired are problems shared. Very often the answers can lie with neighbouring associations who have already experienced and dealt with similar situations. This is why it is important that our member associations continue to share news of their local projects, research, challenges and successes with each other.

The Board is very happy to see members presenting projects for the future:

- We will meet in the autumn 2023 in Valencia, thanks to [@FederacionAICE](#).
- We will have another Symposium in 2024 in Vienna thanks to [@CIA](#).
- [@SUKI](#) of Czech Republic is aiming to organise a new European Friendship Week in the summer of 2024.

All these steps forward from all of you, make us proud of EURO-CIU's members.

Communication

Our main objective is the support of deaf people, in particular cochlear implant users, regardless of their age, cause of deafness, home country, communication method or social background. To raise awareness in society about cochlear implantation and about communication barriers and sensory disabilities, we publish a **Newsletter**, provide an informative website and keep up to date with **Twitter**, **Facebook** and **YouTube**.



In 2022, our website page views from 63.938 unique visitors. The articles with highest readership were "Cochlear implant users demand improved accessibility to communication during the pandemic", "CI day 25th February 2020", "Improve access to cochlear implants for adults" and "Emergency document for use if cochlear implant users become hospitalised". The four most popular pages are "What is the CI?", "About us", "Membership" and "Newsletter".

www.eurociu.eu

EURO-CIU Newsletter

Brian Archbold is Editor of our newsletter and the December 2022 issue was the 53rd edition in which he has been involved. The newsletter is produced four times per year – March, June, September and December – and, occasionally, special editions.

Our Editor holds a secure database under the General Data Protection Regulation (GDPR). We hold only the e-mail addresses of those who have indicated that they would like to receive the newsletter and related e-mails from us. At the end of 2022, there were 1,107 subscribers on our database. Many recipients share and forward the newsletters, so the average readership over the four issues in 2022 averaged over 1,800. The newsletter is read by professionals and manufacturers, many international organisations in the field of deafness and Members of Parliament (both in individual countries and in the European Parliament).

In 2022, over 30 different countries received our newsletter. We have readers not only in Europe but also in the Middle and Far East, the Americas, Australasia and the Indian subcontinent.

Each newsletter has an average of 37 articles. Articles include information about EURO-CIU, other organisations with whom we work, member organisations and other organisations worldwide. The cochlear implant companies give us updates, and we are most grateful for their helpful and interesting insights.

If you know of anyone who would like to receive our newsletter for free, they can contact Brian at newsletter@eurociu.eu. Previous issues can be seen here: <http://eurociu.eu/newsletter>

Social media



Our Facebook page, Eurociu, started in 2017
<https://www.facebook.com/eurociu/>
@eurociu



Our YouTube channel started in 2017 and now features videos produced to coincide with the publication of the Landmark International Consensus Statements.
<https://www.youtube.com/> ► **EURO-CIU Social**



Since starting in 2015 we have posted almost 12.000 tweets.
<https://www.twitter.com/Eurociu>
@eurociu



The board and advisors

- Teresa Amat (Spain), President
- Robert Mandara (Finland), 1st Vice-President
- Beatrice Cusmai (Italy), 2nd Vice-President
- Henri-François Baiverlin (Belgium), Treasurer
- Pieter Bolle (Belgium), Secretary
- Leo De Raeve (Belgium), Scientific advisor
- Brian Archbold (UK), Newsletter
- Fernando Giménez (Spain), Website advisor
- Sari Hirvonen-Skarbö (Finland), EDF representative



Photo: The Board and Advisors: Robert Mandara, Brian Archbold, Teresa Amat, Leo De Raeve, Beatrice Cusmai, Henri-François Baiverlin, Sari Hirvonen-Skarbö, Pieter Bolle and Fernando Giménez

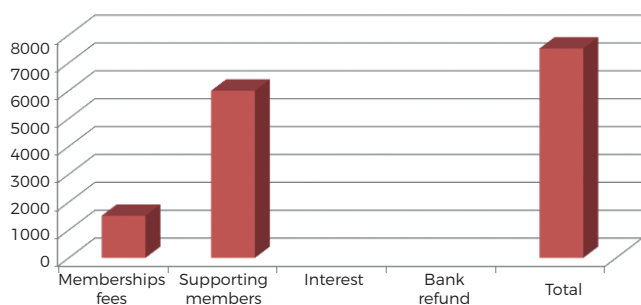
The board normally meets several times each year. Due to the pandemic, our meetings in 2020 and 2021 were all held online. This has been productive and has significantly reduced our travel costs.

Financial situation

2021

Incomes in EUR

Memberships fees	1512
Supporting members	6000
Total	7512

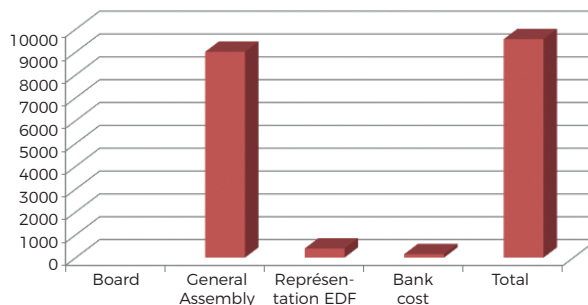


Incomes in EUR 2021

2021

Expenses in EUR

General Assembly	9010
Représentation / EDF	400
Bank costs	152
Total	9562

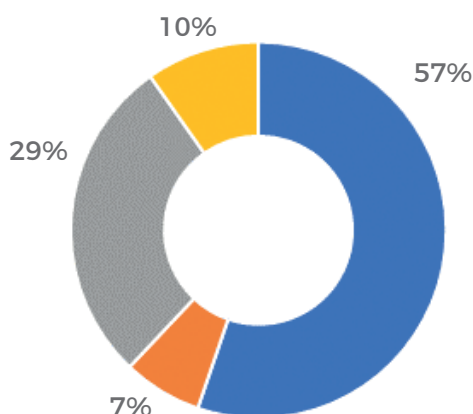


Expenses in EUR 2021

EURO-CIU receives membership fees, support from cochlear implant producers and interest on savings.

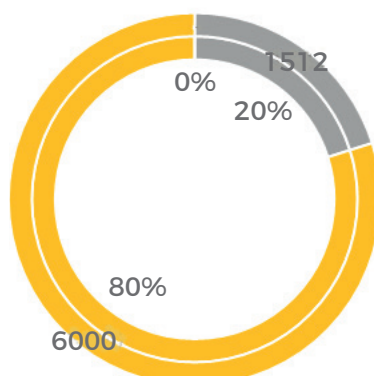
In 2021 our only expenses were for bank costs, multilingual interpretation for the online Annual General Assembly. Due to the pandemic, our expenses were very low because our board meetings and General Assembly were online. Conferences were cancelled, postponed or moved online. Meanwhile our revenues remained stable. In recent years, we saved more than we spent, so our financial situation has improved.

Our revenues in % for 18 years



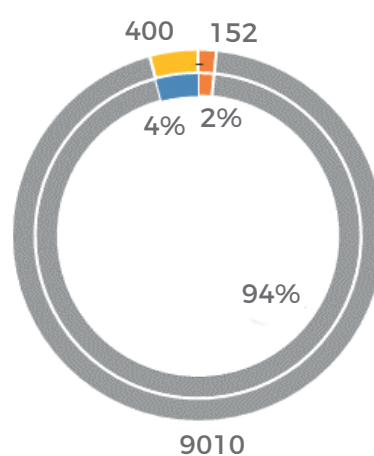
- Gifts
- Membership fees
- Producers support
- Interest

Our revenues in 2021 in EUR and in %



- Membership fees
- Producers support
- Interest + Others

Our expenses in EUR and in % 2021



- Barik costs
- General Assembly + Symposium
- EDF membership fees

EURO-CIU Members

EURO-CIU has 29 full members from 21 European countries, plus five corresponding members.

Full members in alphabetical order:



Austria: Austrian Association For Implantable Hearing Systems / Cochlea Implantat Austria (CIA)
cia@liwest.at, k-h.fuchs@liwest.at, cia.office@ci-a.at, www.ci-a.at



Austria: Österreichische Cochlear-Implant-Gesellschaft (ÖCIG)
info@oecig.at, www.oecig.at



Belgium: Association de Parents d'Enfants Déicients Auditifs Francophones (APEDAF asbl)
e.rioux@apedaf.be, www.apedaf.be, www.facebook.com/apedaf



Belgium: Vlaamse Ouders van Kinderen met Cochleaire Implant vzw (VLOK-CI vzw)
voorzitter@vlok-ci.eu, info@vlok-ci.eu, www.vlok-ci.eu



Bosnia & Herzegovina: EHO Udruženje za podršku djeci/osobama s teškoćama sluha i govora (EHO)
eho.sarajevo@gmail.com, www.facebook.com/eho.sarajevo/



Cyprus: ΠΑΓΚΥΠΡΙΟΣ ΣΥΝΔΕΣΜΟΣ ΓΟΝΕΩΝ ΠΑΙΔΙΩΝ ΜΕ ΑΠΩΛΕΙΑ ΑΚΟΗΣ
Pancyprian Association of parents of deaf children
dkpapach@cytanet.com.cy



Czech Republic: Spolek uživatelů kochleárního implantátu (SUKI)
info@suki.cz, www.suki.cz



Denmark: Cochlear Implant Foreningen (CIF)
formand@cochlearimplant.dk, www.cochlearimplant.dk



Denmark: Decibel - Landsforeningen for børn og unge med høretab (Decibel)
decibel@decibel.dk, <https://decibel.dk>



Denmark: Høreforeningen
mail@hoeforeningen.dk, <https://hoeforeningen.dk>



Estonia: Eesti Implantsaadilaste Selts
selts@implnataadilapsed.ee, app.muil@neti.ee, www.implantaadilapsed.ee



The Finnish Federation of the Hard of Hearing / Kuuloliitto (KHL/CITO)
info@kuuloliitto.fi, www.kuuloliitto.fi



Finland: Sisäkorvaistutelasten valtakunnallinen yhdistys ry (LapCI)
info@lapci.fi, www.lapci.fi



Georgia: Aures Foundation
auresfoundation@gmail.com facebook.com/auresfoundation/ twitter.com/Auresfoundation



Deutsche Cochlea Implantat
Gesellschaft e.V.

Germany: Deutsche Cochlea Implantat Gesellschaft (DCIG)
info@dcig.de, www.dcig.de



Greece: Panhellenic Association of Cochlear Implant Users (CIusers-GR)
ciusers@in.gr, www.ciusers.gr, www.facebook.com/groups/CIusers.GR



Italy: Associazione Genitori e Utenti Audiovestibologia Varese (AGUAV)
segreteria@aguav.it, www.aguav.it



Luxembourg: Lëtzebuerger Associatioun vun de Cochlear Implantéierten asbl (LACI asbl)
laci@iha.lu, www.laci.lu



The Netherlands: Onafhankelijk Platform Cochleaire Implantatie (OPCI)
info@opciweb.nl, www.opciweb.nl



Poland: Stowarzyszenie Słyszeć bez Granic (SSbG)
slyszecbezgranic@slyszecbezgranic.pl, www.slyszecbezgranic.pl



Romania: Asociația Națională a Persoanelor cu Deficiențe de Auz din România Ascultă Viața
asociatiaascultaviata@gmail.com, www.ascultaviata.ro



Slovak Republic: Združenie užívateľov kochleárneho implantátu (ZUKI)
k.klukova@yahoo.com, <https://zuki2.webnode.sk/>



Spain: Federación de Asociaciones de Implantados Cocleares de España (Federación AICE)
jamora@implantecoclear.org, www.implantecoclear.org



Sweden: Barnplantorna-Riksförbundet för barn med cochleaimplantat och barn med hörapparat (BARNPLANTORNA)
info@barnplantorna.se, www.barnplantorna.se



Sweden: Hörselskadades Riksförbund (HRF) The Swedish Association of Hard of Hearing People
hrf@hrf.se, www.hrf.se



Turkey: Cochlear Implant Derneği (CID)
koklearder@hotmail.com, www.koklearimplantdernegi.org.tr



Ukraine: Ukrainian Association of Cochlear Implant Users (UACIU)
uaociu@gmail.com, <https://sluh-e.com.ua>



United Kingdom: Cochlear Implanted Children's Support Group (CICS)
info@cicsgroup.org.uk, www.cicsgroup.org.uk



United Kingdom: National Cochlear Implant Users Association (NCIUA)
secretary@nciua.org.uk, www.nciua.org.uk

CORRESPONDING MEMBERS



Hear now. And always

MED⁹EL



Lehnhardt Stiftung





Contact:

EURO-CIU a.s.b.l. registered in Luxembourg as a non-profit organization.
Registration number: RCS F3180

President's Office:

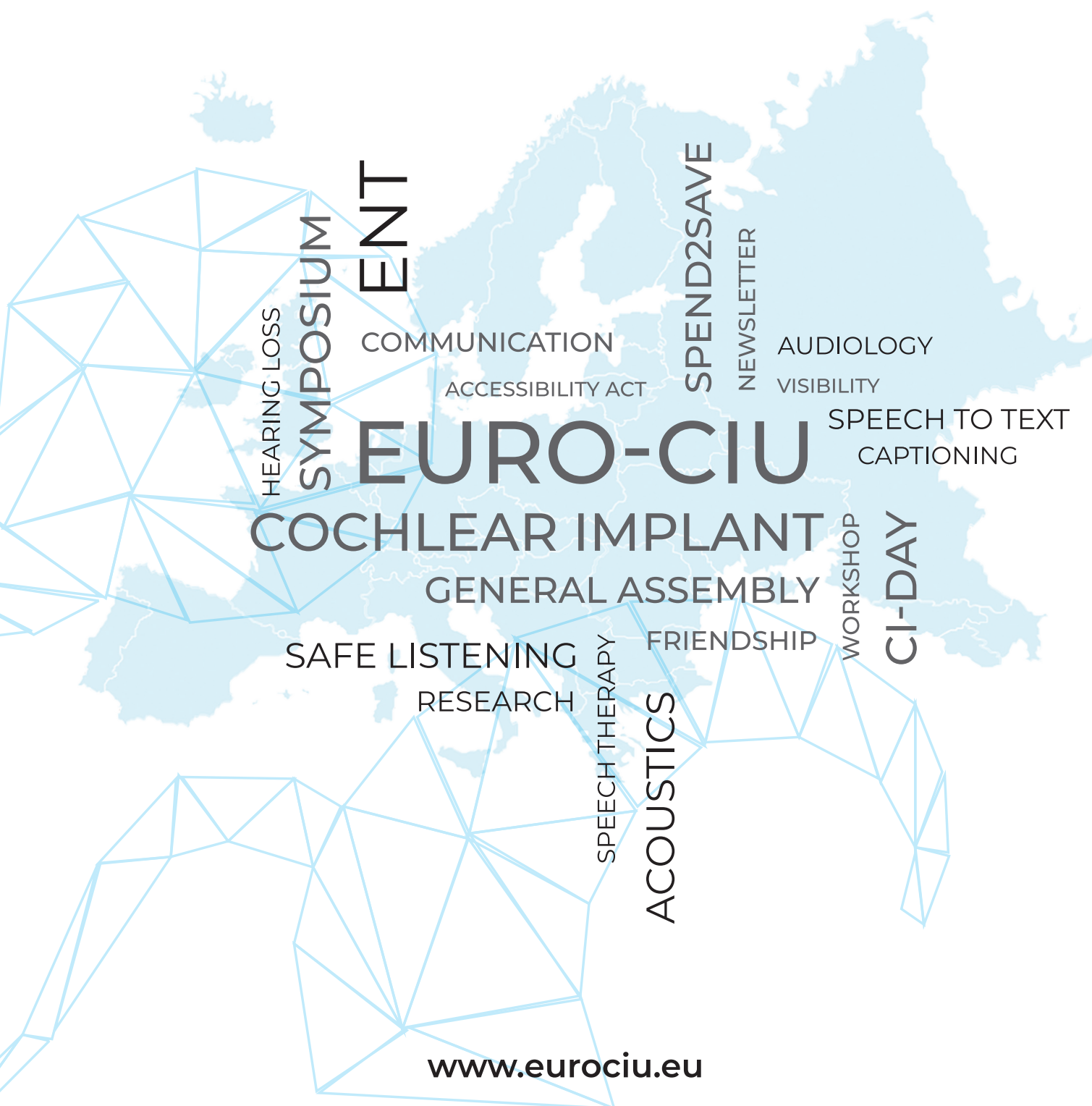
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European Association of Cochlear Implant Users a.s.b.l



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VISIBILITY
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