



EU
ROCIU

ANNUAL REPORT

2017





Acknowledgements:

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EURO-CIU Report 2017

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1.

WHAT IS A COCHLEAR IMPLANT?

The Cochlear Implant C.I. is a technical aid which helps recuperate hearing function in most complete, profoundly or severe deaf cases, by stimulating the acoustic nerve with electric pulses.

The Cochlear Implant consist of an internal part: the receiver, surgically implanted in the mastoid bone behind the ear, with electrodes inserted into the inner ear, (cochlea); and an external part: the microphone and speech processor convert sound into an electrical signal which is sent to the electrodes in the inner ear. These then send the signal through the auditory nerve to the brain, where it is perceived as sound.

2.

WHO CAN BENEFIT FROM A COCHLEAR IMPLANT?



Anyone who suffers from bilateral severe or profound deafness and gets little or no benefit from a hearing aid can benefit from a cochlear implant.

To be a possible candidate for cochlear implantation an adult's hearing loss must be greater than 80 dB (decibels) and a child's greater than 90 dB.

Candidates will undergo a thorough assessment process at a cochlear implant centre.

**The first cochlear implant
was performed in 1957**



**At 2017 there are
around**

150.000

cochlear implant users in Europe



3.

EURO-CIU

FOUNDED IN 1995

EURO-CIU is a non-governmental and non-profit association which was established in Luxembourg in 1995. The association consists of **32 national member associations from 23 European countries**. Altogether the Euro-CIU represents almost 150,000 cochlear implant (CI) users across Europe, approximately 60% of whom are adults and 40% children.

In the Association's recent surveys of members 95% of cochlear implant users state that the implant has improved both their and their families' quality of life.

The **mission** of Euro-CIU is to increase access to the gift of hearing provided by cochlear implantation through awareness and research.

BOARD



Elections for the Board took place during the Annual General Meeting held by Euro-CIU in Helsinki on 20th April 2017, and the following were appointed:

- ▶ **M^a Teresa Amat**
(Spain) President
- ▶ **Sari Hirvonen-Skarbö**
(Finland) 1st Vice President
- ▶ **Ervin Bonecz**
(Hungary) 2nd Vice President
- ▶ **Henri-François Baiverlin**
(Belgium) Treasurer
- ▶ **Beatrice Cusmai**
(Italy) Secretary
- ▶ **Leo De Raeve**
(Belgium) Advisor scientific
- ▶ **Fernando Giménez**
(Spain) Advisor website
- ▶ **Brian Archbold**
(UK) Advisor newsletter



COMMUNICATION & DIFFUSION

Our main objective is the support of deaf people, in particular cochlear implant users, regardless of their age, cause of deafness, home country, method of communication and social background. We must raise awareness in society about cochlear implantation and about communication barriers and sensory disabilities. With this in mind, we publish a newsletter, provide an informative website and keep up to date with twitter, facebook and youtube. In 2017 we started working in a new communication plan you will see the fruits of during 2018. We opened a facebook page, changed our EURO-CIU logo and new website, look us up and see all the changes!



NEWSLETTER

A digital newsletter is sent 4/5 times a year with information from the cochlear implant world, our members, etc. If you would like to subscribe for free, send us an email at:

newsletter@eurociu.eu

You will be joining more than

2080 subscribers and

115 articles/year from an average of at

least **7** countries each number.



You
Tube

FACEBOOK / YOUTUBE

Our new facebook & youtube page started this 2017.

Check it out!
Like us!



WEBSITE

Created in 1996, at the end of 2017 our website

had
1.684.946
visits
www.eurociu.eu



TWITTER

Since starting in 2015, we have increased our twitter presence tenfold. At the end of 2017 we had

325 followers, around
2253 likes and

more than **2812** tweets.

66% of our followers are between 25 and 44 years old, and mainly (**63%**) are women.

Twitter.com/eurociu
@eurociu

GOALS

FOR ADULTS AND CHILDREN

1. Children and adults with severe to profound hearing loss must be offered cochlear implants (both unilateral and bilateral) when they meet the criteria, and **the costs should be covered by the national health care system.**
2. The **criteria for cochlear implant candidacy** in both children and adults should be based not only on an auditory threshold of 80 or 90 dB, but also taking account of the benefit of individual's hearing aids, so that some patients who do not reach the audiological criteria can still be candidates for a CI.
3. The **decision** as to whether **to undergo cochlear implantation** must be dependent upon the informed consent of the individual involved, or their parents in the case of children, and also upon the recommendation of a **multi-disciplinary CI team**. All cochlear implant candidates, or parents in the case of children, must be fully informed of the entire process including the pre-operative assessment, the surgical procedure, and the post-operative rehabilitation program.
4. In accordance with the principles of the UN Convention on the Rights of Persons with Disabilities (2006), **assistive technologies enhancing an individual's full participation and inclusion in society should be made available**. Recognizing the importance of such devices for the inclusion of people with hearing loss in all aspects of life, EURO-CIU encourages all European countries to establish health programs providing hearing rehabilitation to all, including the supply of hearing aids, cochlear implants and other assistive devices.





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

- 5. Accessibility** must be of 'universal design', otherwise it is not really accessible to all. Universal design means that the design of products, environments, programmes and services must be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.
Universal design, shall not exclude assistive devices for particular groups or persons with disabilities where this is needed (UNCRPD 1).
- 6.** Cochlear implants are **cost effective** using any current cost benefit measure which takes into account the impact on all quality of life, the enhancement of communication, social functioning, independence, educational achievement and employment opportunities, the reduction in mental health problems and cognitive decline.
- 7. All professionals** supporting CI-users should have up-to-date knowledge to ensure that they can properly support children and adults using CIs. More training needs to be put in place to ensure that all professionals are fully aware not only of the latest developments in cochlear implantation but also of those in other technologies and interventions in the field of hearing loss.

SPECIFIC FOR CHILDREN

- 1.** EURO-CIU endorses **early detection and intervention** for infants with hearing loss in order to maximize the potential for development of listening skills, speech and literacy for children who are deaf or hard of hearing. The hearing of all babies **should be screened at birth, or no later than 1 month of age**, and those with a confirmed hearing loss should receive appropriate **family centred early intervention** and the **most appropriate hearing solution (hearing aids or cochlear implant) at no later than 6 months of age** if the family chooses it to.
- 2.** In the case of limited speech perception with these hearing aids **infants should be referred for assessment for cochlear implantation preferably before the age of 9 months and no later than the age of 18 months**.
- 3.** Because of the proven enormous benefits of binaural hearing, **bilateral cochlear implantation** or **bimodal hearing** (a CI and a hearing aid) should be provided **before the age of 12 months and no later than the age of 2 years**. In the case of sequential bilateral implantation, the gap between the first and second should be kept as short as possible, with the minimum of 3 months and a maximum of 2 years.
EUROPEAN ASSOCIATION OF COCHLEAR IMPLANT USERS a.s.b.l.
- 4.** The ability of a child to benefit from a cochlear implant is directly related to the **provision of high quality rehabilitation**. To maximise the potential benefit of a ci there must be continual emphasis on the development of listening skills. A co-ordinated multi-disciplinary approach is essential to ensure optimal outcomes.
- 5.** There is evidence that 30-40% of deaf children have additional needs. Therefore a **multi-disciplinary team must be involved in monitoring deaf children** so that additional difficulties can be identified as soon as possible and appropriate additional intervention or therapies can be introduced when necessary.
- 6.** Children with cochlear implants must have access to **inclusive, high quality, free education** on an equal basis with others in the communities in which they live (UNCRPD). Children with cochlear implants who have no additional needs can be integrated in mainstream schools and have the potential to achieve the same educational outcomes as their hearing peers allowing them access to higher education and improved employment opportunities.
- 7.** All professionals who support deaf children in mainstream or special educational provisions **should have specialist training** in the needs of deaf children.

AWARENESS - OUR AIMS



RESEARCH

1. **Highlight the costs** to society of not dealing effectively with hearing loss.
2. Support not only **early hearing screening** for all new-borns, but also for adults from the age of approximately 55.
3. **Improved training for doctors and audiologists** regarding the potential benefits of cochlear implantation for adults and older patients is required.
4. Advance **awareness of best practices** related to cochlear implants among patients and their families, clinicians including primary care doctors and other health professionals, early interventionists, educators, policy-makers, payers and the general public.
5. **Educate and encourage policy-makers and public health authorities** to take steps to increase access to cochlear implantation.
6. **In collaboration with other organizations**, undertake efforts to promote cochlear implantation as the standard treatment for severe/profound deafness.

1. Euro-CIU **encourages and supports research on all aspects relating to cochlear implantation** including the selection of (re)habilitation for all CI users regardless of age.
2. Euro-CIU **supports an annual conference or workshop** held by a member country's Association to highlight research, clinical issues, (re)habilitation, quality of life, cost effectiveness, healthcare policy, insurance issues, etc.

To remain a free and accessible society Europe must be a place where everyone is heard. Deaf people can hear and listen thanks to cochlear implants. Now it is the national and European administrations' turn to listen to us!

4.

C.I. DAY

I ♥
CIHAPPY INTERNATIONAL
COCHLEAR IMPLANT DAY

February 25 has been designated International Cochlear Implant Day because on that day in 1957, two French doctors, Andre Djournio and Charles Eyries were the first to electrically stimulate the auditory nerve by placing an electrode outside the cochlea. In 2017 we celebrated the 60th anniversary of this event with a special logo shared to all Europe and beyond.

The first International Cochlear Implant Day was held in 2009 by the Spanish CI-users organisation Federacion AICE, and since then more than 40 different countries all over the world have adopted this day to create awareness of cochlear implantation and to raise positive media attention the topic.

5.

SYMPOSIUM WORKSHOP



One of our main objectives is to organise events where we can work with and learn from each other as well as support the particular our country member which hosts the event.

Each year we alternate between a big Symposium and a Workshop in different parts of Europe. In 2015, we celebrated our 10th European Symposium in Antwerp, Belgium, with the title 'State of the Art on Cochlear Implants'. In 2016, we went to

Varese, Italy for a workshop on quality of life and rehabilitation strategies for CI users. In 2017, Helsinki, Finland, a 3 day event was hosted for our 11th Symposium, joining the Finnish celebration of their 100th anniversary as an independent state. Around 300 participants from all the Scandinavian and north European countries participated in this event "Living with a CI" which focused on: design for all, accessibility to education, peer support and rehabilitation, health economics, and mainly in multilingualism and music and cognitive development.

In 2018, Barcelona, Spain, will host our Workshop "Walking together towards the future" where all members can join ideas about the path forward for Cochlear Implant Users.

6.

YOUTH
EFWThe Ear
Foundation

EURO-CIU with **The Ear Foundation** collaboration, organises a summer camp in England for cochlear implant kids from 11 to 16 years old. The week consists of games and activities, day trips into Yorkshire and a unique opportunity to make friendships with other cochlear implant users from around Europe, while the week is staffed by Teachers of the Deaf, Speech and Language Therapists, and

staffs from The Ear Foundation and members of our EURO-CIU national organizations, who are all experienced in working with young deaf people or are deaf people themselves.

In 2016, European Friendship Week, we were inspected by UK Ofsted and were awarded OUTSTANDING in all areas, which we were delighted to receive.

"I'VE LEARNT THAT ITS OK TO BE DIFFERENT –
HERE THERE ARE ALWAYS PEOPLE IN THE SAME SITUATION"



"IT MAKES YOU MORE OPEN TO LEARN ABOUT OTHERS AND YOURSELF"

7.

EURO-CIU IS A MEMBER OF...



European Platform of
Deafness, Hard of Hearing,
and Deafblindness

PLATFORM

EUROPEAN ASSOCIATION OF COCHLEAR IMPLANT

The Platform has been formed to enhance, strengthen and cultivate a robust and enduring collaboration between the European Cochlear Implant Users (EURO-CIU), the European Deafblind Network (EDbN), the European Federation of Hard of Hearing People (EFHOH), the European Federation of Parents of Hearing Impaired Children (FEPEDA) and the European Union of the Deaf (EUD), for the express purpose of benefiting Deaf people (including sign Language users), Hard of Hearing people, deafened people, and Deafblind people and their families regardless of the language, the communication system or the assistive technologies they use (hearing aids and cochlear implants). We aim to strengthen the EU 2020 strategy and the EU Disability Strategy as regards to full and equal participation in society with the main aim in achieving a society without Communication Barriers.

info@epdhdb.eu

Follow us: @EPDHDB <http://www.epdhdb.eu>





EDF

The European Disability Forum is an independent NGO that represents the interests of 80 million Europeans with disabilities. It is a unique platform which brings together representative organisations of persons with disabilities from across Europe. EDF is run by people with disabilities and their families.

EURO-CIU supports EDF's campaigns to achieve a "Strong Accessibility Act". Together, EURO-CIU and EDF are a strong, united voice of persons with disabilities in Europe.

www.edf-feph.org



European Commission

EUROPEAN DAY OF PERSONS WITH DISABILITIES 2017 AND 4TH EUROPEAN DISABILITY PARLIAMENT

We are represented at big events in the European Commission and European Parliament with MEPs to explain our specific needs, to raise awareness and to have input into policies relating to deafness and communication barriers as well as disability in general. One of the next fights we have started this year is to have 2019 European Elections accessible to communication for all voters, including Cochlear Implant Users!

<http://ec.europa.eu/social/main.jsp?langId=en&catId=88&eventId=1152&furtherEvents=yes>



8.

STRONG ACCESSIBILITY ACT



Thanks to the efforts of the last few years, EDF (European Disability Forum) and us in our shared part, EURO-CIU, we all are overjoyed to announce the European Council has accepted to start the trialogs (dialogs) and negotiations between the European Parliament, the Council and the Commission about the #AccessibilityAct during 2018. We will keep working to have a Strong Accessibility Act! And make Europe administrations and politicians to stand by their words of support and uphold our rights as #WeAreCitizens and vote too!



EURO-CIU members with Members of the European Parliament, as well as other representatives from NGO's, supporting a Strong Accessibility Act.



Users and families are key. “We need to convince users and potential users of hearing technology and ensure they have a story and public voice and they should use it... sensitisation and awareness”

“Policy changes only ever occur over long periods of time, and typically come from a bottom up initiative”.

“WHO and this (Spend2Save) combined together is really important and we have a great opportunity.”

Specific Areas of work:

There were some specific areas where the campaign could help develop and promote policy that spanned a number of countries concerns or needed implementing across Europe:

Develop National Action Plans on Hearing Loss-

Members of the World Health Assembly agreed to have national action plans when they supported the resolution and a few countries have done so. The UK Action Plan on Hearing Loss and its implementation is one example to promote hearing loss as a public health and social policy issue for Governments and funders of services. Agreed to develop an Action Plan template for countries to adapt for their local needs, including users in the development.

Adult Screening- The establishment of Adult Screening programmes is a major





challenge across most European countries: a campaign for adult hearing screening needed. Sharing current data on importance of early intervention, links to cognitive decline and mental health issues, and economic impact.

Accessibility Act/Standards of Quality Hearing Care-

The sector has already been successful in establishing European wide standards around the quality of Hearing Aid provision. The next stage should be implementation in EU countries in their healthcare protocols with legislative levers to establish greater funded entitlements of the provision of Quality Hearing Care, access to long-term services, assistive devices and

other technologies. Greater communication access, particularly via speech to text services, must be included. Empowering users with the knowledge of what to expect from hearing care specialists.

Hearing Loss and Dementia- It is clear from the recent work of the Lancet commission and other research such as Amieva et al., (2016) that addressing hearing loss in middle age could help reduce the overall incidence of cognitive decline but, we need to do much more to disseminate what we know already and promote further the understanding of the impact of hearing loss on dementia.

“WHO has finally passed the resolution and in two years’ time we have a report in our hand. The most important thing is user representatives are pressing for change.”

Thanks to EURO-CIU members, The Ear Foundation and Cochlear support, the Spend2Save summary has been translated to several languages.

10.

MANIFESTO



EURO-CIU joined a stakeholders Coalition to raise awareness among the European policy makers on the social and economic impact of hearing loss and ear diseases with the "Manifesto on Hearing Loss and Disability" of European Health First.

In Europe, 10% of the total population (52 million people) self-report to experience hearing loss, 73% consult a medical professional, but only 50% are referred to hearing care professionals. Hearing loss is a huge problem for the health of Europe's citizens, threatening to put huge pressure on Europe's health and social care systems if left untreated. Innovative medical technology, such as hearing aids and hearing implants, can alleviate the burden. Action from European policy-makers is called to help raise awareness of this condition, look at elective ways of prevention, facilitate access to these technologies where appropriate, improve care and share best practices amongst Member States.

"The Coalition of Hearing Loss and Disability demands concrete actions to tackle hearing loss and improve access to hearing technologies"

Download the manifesto:
eurociu.eu/manifesto-on-hearing-loss

Manifesto on Hearing Loss and Disability



11.

VISIBILITY

A.

INTERNATIONAL RELATIONSHIPS



WHO

World Health Organization 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. In cases where hearing loss is unavoidable, we raise awareness to ensure access to appropriate and affordable assistive technologies such as hearing aids and surgically implanted electronic cochlear implants, and communication services like speech therapy, sign language and captioning.

<http://www.who.int/pbd/deafness/world-hearing-day/WHD2017Posters.pdf?ua=1>



ACI

American Cochlear Implant Alliance and EURO-CIU have reached an agreement to exchange resources and include each other in our websites.

B. MEETINGS



EURO-CIU has met with European politicians & Producers representatives.

C. CONFERENCES

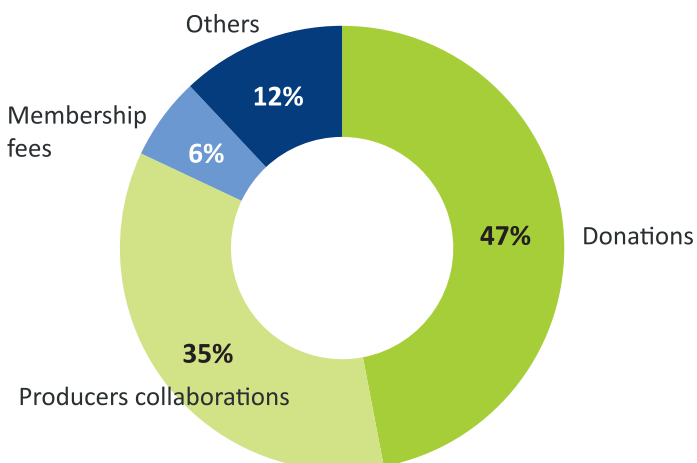
EURO-CIU has been present at European and International Congress: ESPCI (European Symposium on Paediatric Cochlear Implant), APSCI (Asia Pacific Symposium on Cochlear Implants and Related Sciences), Nordic Congress, and put stands at national congress.



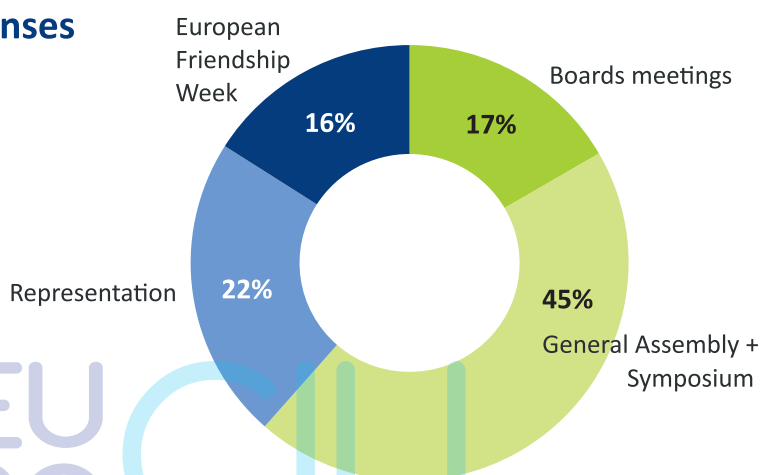
12.

ECONOMIC INFO

Our revenues



Our expenses



13.

SUPPORTING MEMBERS



www.cochlear.com



www.advancedbionics.com

MED[®]EL

www.medel.com

oticon
MEDICAL

www.oticonmedical.com



www.earfoundation.org.uk



Prof. Ernst Lehnhardt-Stiftung

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14.

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Portugal. Associação Portuguesa de Portadores de Próteses e Implantes Auditivos (OUVIR)



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Rumania. Asociația persoanelor cu deficiențe de auz "Ascultă Viața!" (Ascultă Viața)



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Serbia. Kohlear Implant Info Udruženje



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Slovakia. Združenie užívateľov kochleárneho implantátu (ZUKI)



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Spain. Federación de Asociaciones de Implantados Cocleares de España (Federación AICE)



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Sweden. Riksförbundet för Barn med Cochleaimplantat och Barn med Hörapparat. (Barnplantorna)



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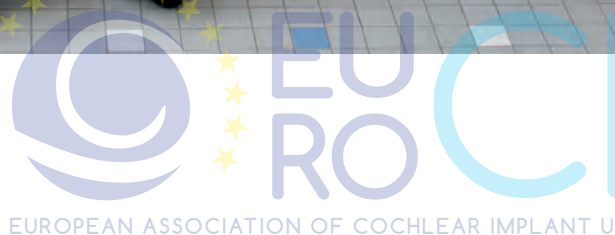
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 **EACIU**
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