



EURO-CIU

ANNUAL REPORT

2016





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EURO-CIU Report 2016

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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 2016 there are
around

150.000

cochlear implant users in Europe



3.

EURO-CIU

EURO-CIU is a non-governmental and non-profit association which was established in Luxembourg in 1995. The association consists of 27 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.

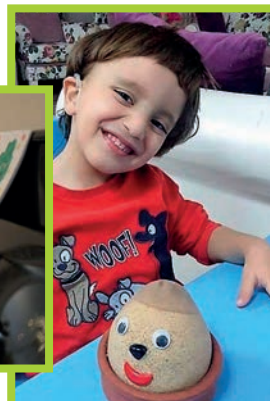
The **mission** of Euro-CIU is to increase access to the gift of hearing provided by cochlear implantation through awareness and research.



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 U.N. 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.





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.
- 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

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.

RESEARCH

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.

BOARD

Elections for the Board took place during the Annual General Meeting held by Euro-CIU in Antwerp on 11th April, 2015, and the following were appointed:

In the main picture below the top row from left to right and then the lower row from left to right shows:

- ▶ **Leo Raeve** (Belgium) Adviser scientific.
- ▶ **Fernando Giménez** (Spain) Adviser website.
- ▶ **Brian Archbold** (UK) Adviser Newsletter.
- ▶ **Henri-François Baiverlin** (Belgium) Treasurer.
- ▶ **Epp Müil** (Estonia) secretary.
- ▶ **Sari Hirvonen-Skarbö** (Finland) 1st Vice President.
- ▶ **Søren Rasmusen** (Finland) 2nd Vice President.
- ▶ **M^a Teresa Amat** (Spain) president.



5.

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.



WEBSITE

Created in 1996, at the end of 2016 our website

had

1.420.918

visits

www.eurociu.eu



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: info@eurociu.eu with "newsletter subscription" in the subject of the email. You will be joining more than

2065

subscribers



TWITTER

Since starting in 2015, we have increased our twitter presence tenfold. At the end of 2016 we

had **175** followers,

around **500** likes

and more than **780** tweets.

On 29th November 2016, twitter.com/eurociu became the trending topic in the whole of Belgium with **#EDPD2016** about the Day of Persons with Disabilities hashtag.

6.

C.I. DAY

INTERNATIONAL
COCHLEAR
 IMPLANT DAY
 25 FEB 2016

Hear now. And always



MED^{EL}

Happy
 #CochlearImplantDay



oticon
 MEDICAL | Because sound matters

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 will be celebrating its 60th anniversary of this event.

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.

1.

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'. Last year, 2016, we went to Varese, Italy for a workshop on quality of life and rehabilitation strategies for CI users. In 2017, Helsinki, Finland, will host our 11th Symposium, joining the Finnish celebration of their 100th anniversary as an independent state.



8.

YOUTH EFW

The 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"

9.

EURO-CIU IS A MEMBER OF...

EUROPEAN
DISABILITY
FORUM

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.

EDF is a front runner for disability rights. Together, EURO-CIU and EDF are a strong, united voice of persons with disabilities in Europe.

www.edf-feph.org



EURO-CIU Board members with Yannis Vardakastanis EDF president and Catherine Naughton EDF Director.





European Platform of
Deafness, Hard of Hearing,
and Deafblindness

PLATFORM

The Platform has been formed to enhance, strengthen, and cultivate a robust and enduring collaboration between the European Cochlear Implant Users Association (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 method of communication or the assistive technologies they use (hearing aids and cochlear implants).

<http://www.epdhdb.eu/>



European Commission

EUROPEAN DAY OF PERSONS WITH DISABILITIES 2016

At the Platform meetings, our President has discussions with many 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. In the last two years, we have been invited to participate in the European Day of Persons with Disabilities celebration organized by the European Commission which is attended by disability organizations and politicians from all around Europe.

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

10.

CAMPAIGN SPEND TO SAVE

Hearing Loss is a major unaddressed across Europe which leads to substantial individual and to public services.

...y's hearing aids and implants change this:

...atest hearing technologies, including hearing and implants, have been shown to change ...es of those with hearing loss and to be cost ...ive (Alfonis, 2012; Perez & Edmonds, 2012; Bond, 2008)

...ase of hearing aids and cochlear implants ...ases employability and earning power ... (Ker, 2010; Clark, 2015)

...use of hearing aids is associated with less ...gnitive decline (Ker, 2015)

Hard of hearing people are significantly less embarrassed to wear hearing aids and users are more satisfied in 2015 compared to 2009 (Shama-Aronson, EuroHSA)

- There is great variation across Europe of utili of hearing technologies such as hearing aid cochlear implants: for example, for hearing Spain has 2.8 per 1,000 population and DE has 22.4 per 1,000

- For the people with self-reported hearing average of 29 countries is 53% uptake to aids. Nine countries do 10% better than countries are within 10% and sixteen or more than 10% below

- In European countries hearing technologies associated with use of primary care and in hearing loss is lower

- In many countries slow; for example Poland who could benefit more

- People with hearing value on the benefit

- Criteria and access great deal across countries

SUMMARY ADULT HEARING LOSS: EUROPE'S GROWING CHALLENGE Investing in hearing technology improves lives and saves society money

Hearing loss is one of the most challenging health and social issues facing Europe. Communication defines us and underlies our ability to function in the world: to relate to family, friends and partners, have a job, lead productive lives and maintain our health and wellbeing through social connections. Hearing loss robs us of the ability to communicate and therefore impacts on every facet of life. Yet its impact often goes unnoticed and unaddressed.

- 51 million adults across Europe have hearing loss and this number is growing (EuroHSA 2016)
- Hearing Loss is the number one cause of Years Lost to Disability in those over 70 in Western Europe (Davis 2016)
- Those with severe hearing loss are at five times the risk of developing dementia as those with normal hearing (Lin 2013)
- In older age people with hearing loss are at greater risk of social isolation and reduced mental well-being (Smeets 2009)
- Older people with hearing loss are at greater risk of social isolation and reduced mental well-being (Smeets 2009)



"...you lose self-esteem, you don't want to mix, anything like that because that's what I do."



With support from Euro-CIU our associate member, The Ear Foundation organised a conference in Brussels entitled "Adult Hearing Loss: Europe's growing challenge". This conference was a platform to launch their latest report "Spend to Save" (see the website at the end of this article).

"The evidence is now clear that the cost of NOT providing hearing technologies has been shown to be greater than the cost of providing them."

After the success of neonatal screening, the fight is now on to achieve adult hearing screening.

Older people with hearing loss are two and half times more likely to experience depression than those without hearing loss (Mathews 2013) and are also at increased risk of major depression (Davis 2011).

Social isolation has an effect on health (Cohen 1995) and in older people there is

a strong correlation between hearing loss and cognitive decline (Lin 2013), mental illness and dementia (Lin 2011) and premature death (Friburg 2014, Contrera 2015).

The cost effectiveness of the latest technologies is now proven and all speakers endorsed the report which recommends that funding schemes should include the full cost of hearing aids and cochlear implants, as well as the introduction of National Adult Hearing Screening Programmes, as this would ultimately save money overall for health, social care and welfare systems.

For more information and the full PDF summary: www.eurociu.eu/spend2save

11.

VISIBILITY

A. MEETINGS



Shelly Chadla, WHO (World Health Organization) hearing program director ▶



▲ Helga Stevens, Member European Parliament

B. CONFERENCES



C. STANDS



12.

AGREEMENTS

A.
BEATS OF
COCHLEA



This event is organized by World Hearing Center of the Institute of Physiology and Pathology of Hearing in Poland in partnership with EURO-CIU

The International Festival for Children, Youths and Adults with Hearing Disorders 'Beats of Cochlea' is the cherished initiative of Prof. Henryk Skarzynski which aims to present the progress of hearing implant medicine and technology through the musical successes of CI users. 2016's event also celebrated the 25th anniversary of the first cochlear implantation in Poland performed by Prof. Henryk Skarzynski and

the 20th anniversary of the Institute of Physiology and Pathology of Hearing.

Ms Agata Kornhauser-Duda, the wife of the President of Poland, honoured the 2nd Festival 'Beats of Cochlea' with her patronage emphasised the importance of increasing the public awareness of hearing problems and need for early intervention.



B. THE EAR FOUNDATION



After several years cooperating in summer camps and other projects with The Ear Foundation, EURO-CIU and TEF have consolidated their relationship with a written agreement they signed in 2016.

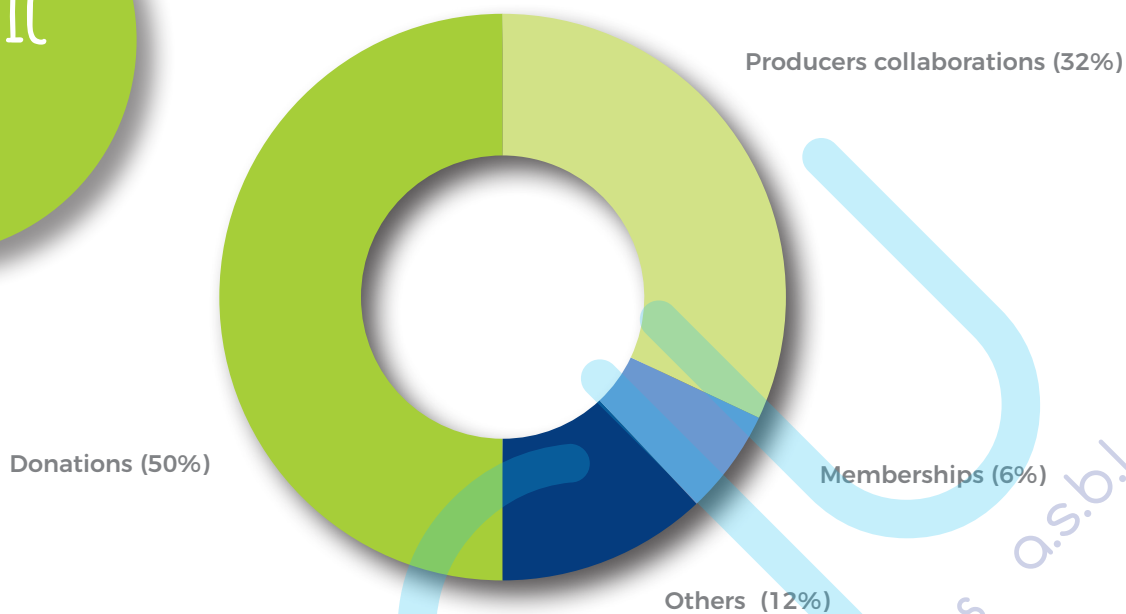
C. MEDICAL EARONE PROJECT



The project lead by Pr. Bernard Fraysse Professor of Universities from the Hospital Physician Head of the ENT department CHU of Toulouse, wants to create a proposal for a European registry for cochlear implants in children, to be submitted in response to the Horizon 2020 call for Networking and optimising the use of population and patient cohorts at EU level, ref. SC1-PM-04-2016; by researching neonatal screenings and comparing the optimal surgical evaluation, follow-up and rehabilitation.

13.

ECONOMIC INFO



14.

SUPPORTING MEMBERS



www.cochlear.co.uk



www.bionicear-europe.com

MED⁹EL

www.medel.com

oticon
MEDICAL

www.oticonmedical.com



www.earfoundation.org.uk



Prof. Ernst Lehnhardt-Stiftung

www.lehnhardt-stiftung.org

15.

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Denmark. Cochlear Implant Foreningen



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Denmark. Familieforeningen for Cochlear Implanterede Børn (DECIBEL)



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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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Sweden. Hörselskadades Förening Västplantorna (HRF-VIS)



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Turkey. Cochlear Implant Derneği (CID)



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Poland. Stowarzyszenie Słyszeć Bez Granic (SSBG)



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



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Romania. Asociația persoanelor cu deficiențe de auz "Asculța Viata!" (Asculța Viata)



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



EURO-CIU

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