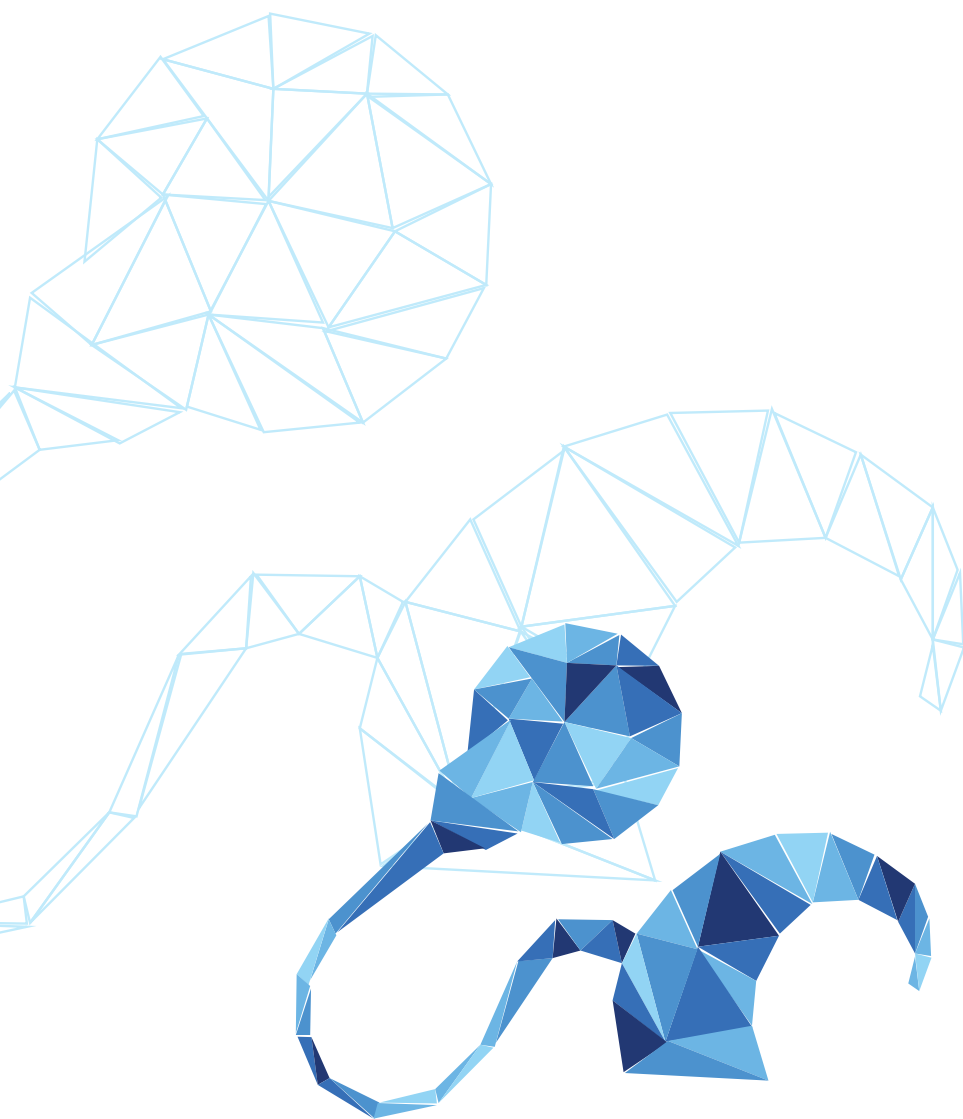




European Association of Cochlear Implant Users a.s.b.l



ANNUAL REPORT 2018



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EURO-CIU Report 2018

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WHAT IS A COCHLEAR IMPLANT?

The **Cochlear Implant (short version: CI)** 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.

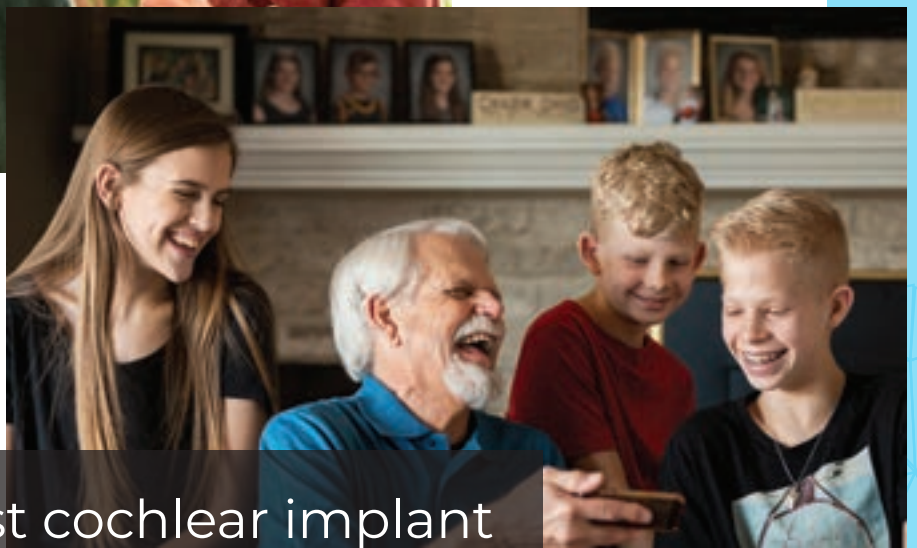
The Cochlear Implant consist of an internal part: the receiver, surgically implanted in the mastoid bone behind the ear, with electrodes inserted into the inner ear, (cochlea); and an external part: the microphone and speech processor convert sound into an electrical signal which is sent to the electrodes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



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 2018 there are around
220.000
cochlear implant users in
Europe.



EURO-CIU

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 24 European countries**. Altogether the Euro-CIU represents more than 220.000 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.

THE BOARD



From left to right:

Ervin Bonecz (Hungary) | *2nd Vice President*, **Beatrice Cusmai** (Italy) | *Secretary*, **Ma Teresa Amat** (Spain) | *President*, **Sari Hirvonen-Skarbö** (Finland) | *1st Vice President*, **Henri-François Baiverlin** (Belgium) | *Treasurer*

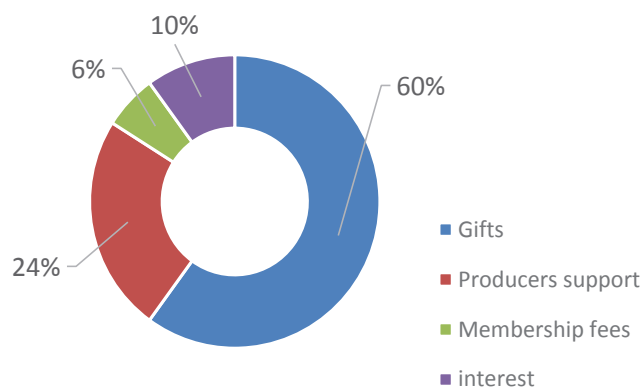


From left to right:

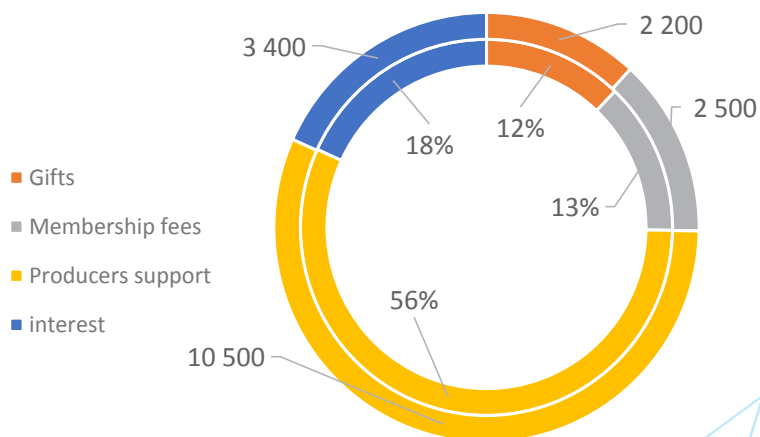
Leo De Raeve (Belgium) | *Advisor Scientific*, **Fernando Giménez** (Spain) | *Advisor Website*, **Brian Archbold** (UK) | *Advisor Newsletter*

FINANCIAL SITUATION

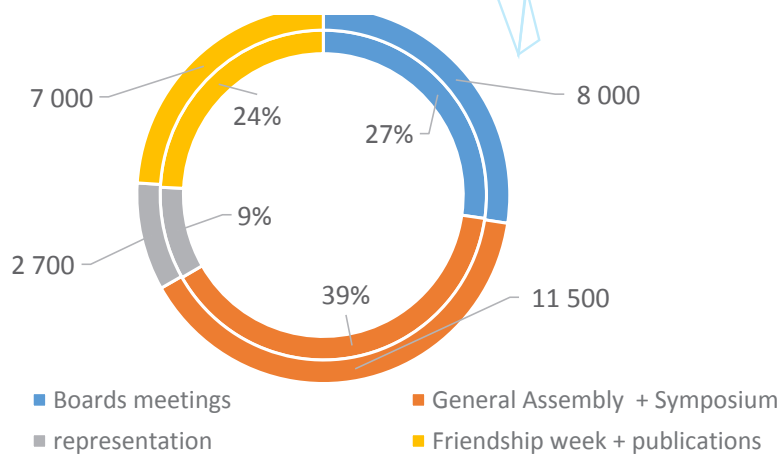
OUR REVENUES IN % FOR 15 YEARS



OUR REVENUES IN 2018 IN EUR AND IN %



OUR EXPENSES 2018 IN EUR AND IN %





COMMUNICATION AND VISIBILITY

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. We opened a Facebook page, in 2018 we changed our logo and builded a new website, look us up and see all the changes!

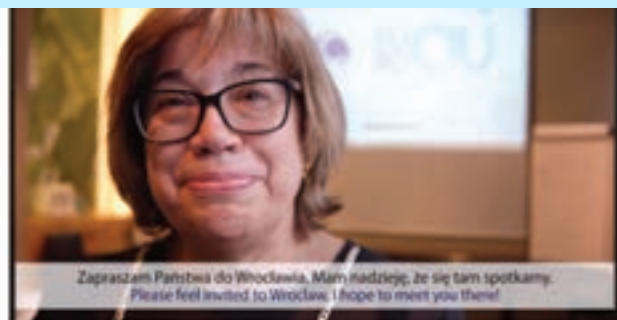
EURO-CIU NEWSLETTER

The quarterly EURO-CIU Newsletter is widely read, with the last edition being seen by 2,042 people over 39 countries. Although the majority of our readers are in Europe, we have regular readers in South America, North America, Africa, Middle East, Russia, Far East, Australia and New Zealand. On our database, we include Members of Parliament and Members of the European Parliament when they are known to us; as well as senior directors from national and international organisations for the deaf, and also from such important international bodies like the World Health Organization. It is pleasing to note that many of our member organisations forward the Newsletter to their national governments.

Over the last year, each edition of the Newsletter has had an average of 32 articles; and it is particularly encouraging to learn about the activity of our member organisations. We are most grateful to those countries who regularly send us articles, so that we may share ideas and best practice.

EURO-CIU takes the General Data Protection Regulation (GDPR) seriously. GDPR covers how organisations can use our members' information and their rights relating to that information. Our members' privacy is very important to us, and we have undertaken only to make contact in relation to EURO-CIU Newsletters and relevant information about Workshops, Conferences and General Assemblies. Since contacting recipients of the Newsletters about GDPR, 39 people have asked to be unsubscribed from receiving our Newsletters. In each case, the Editor of the Newsletter has written to them individually, confirming that their name has been taken off the Newsletter database.

If you would like to subscribe for free, send us an email at:
newsletter@eurociu.eu



We just ended a few weeks of celebrations utterly related to our group, at European and #CochlearImplantDay on 25th February, the #WorldHearingDay on 3rd March, the Euro March. All of them united rejoice on #hearing, #rehabilitation, #CochlearImplants, #Hear #WeLikeToHear!

EURO-CIU has been present on the World Health Organization @who, in the European



In this issue

- President's Message
- Message from the Editor
- EURO-CIU SYMPOSIUM 2019 AND GENERAL ASSEMBLY
- EUROPEAN FRIENDSHIP WEEK - Sunday 21st July - Saturday 27th July 2019
- European Parliament Elections
- International Cochlear Implant Day
- WHO launches the hearWHO app for mobile devices to help detect hearing loss
- ESTONIA - Welcome to the Summer Week in Estonia
- FINLAND - Hearing Bus - the great success
- GERMANY - DCHG - Deaf Youngsters go Europe
- ITALY - AGUAV - Ministry of Health, Rome
- SPAIN - First research on Bullying in cochlear implant users in Spain

SOCIAL MEDIA

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.



Our new Facebook page started in 2017.



Our Youtube channel started in 2017.



At end of 2018 our website had

1.684.946 visits.



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.



We are getting our message across in social media. According to twitter analytics in 2018 EURO-CIU Twitter got **181.800** impressions and the data shows most of them are women (62%) in front of men (38%). We now have **more than 500** followers and in November, we reached the nice figure of **4444** tweets since we started.

CI-DAY

February 25 has been designated International **Cochlear Implant Day** because on that day in 1957, two French doctors, **Andre Djourno** 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.



The slogan for **#CI-Day18 "NoLimits"** has broken all barriers and frontiers. The International Cochlear Implant Day is celebrated now in more than 60 places in the world. Cochlear Implant companies, users, families, professionals, hospitals, etc. all united to raise awareness on **#HearingLoss**, **#CochlearImplant** and **#CochlearImplantDay**. Professional dancer **#CochlearImplant** protagonist this year, **Simone Botha**, said: *"Life isn't perfect. No one is perfect. But as #CochlearImplant Users have #NoLimits we are preparing to #HearTheFuture."*

Simone Botha, a cochlear implant user since she was 22 months old, is a professional dancer who was chosen to advertise a brand of gyms around the world. Last year, the gym's advertising agency edited, deleting her cochlear implant, showing society still has a lot to learn about being inclusive and eliminate stigmas.

"This is a billboard picture of me posing for Virgin Active and if you don't know me personally then you won't miss the tiny piece that is a cochlear implant that is supposed to sit on my head. They just went and without my permission decided to edit the cochlear implant out, because why!??? It doesn't fit with their pretty little picture of portraying the perfect life that is Virgin Active? Well guess what? Life isn't perfect. No one is perfect."

| Instagram @bothisimone



"We issued an immediate apology to Simone. We will work with Simone around education and have re-run the campaign, un-retouched. We 100% accept that the action of photo-shopping the image is not in line with our values as a business, nor in keeping with the welcome we extend to everyone."



Virgin Active swiftly removed the edited photograph and had a meeting with the model.

During our International Cochlear Implant Day 2018 celebration EURO-CIU shared this story to raise awareness as Simone said:

"Thanks to the Cochlear Implant, there are no limits!"

Her profession related with music is a clear proof of that.

"Cochlear Implant:
no limits!"

SYMPOSIUM | WORKSHOP GENERAL ASSEMBLY

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.



WORKSHOP: BARCELONA 2018

In 2018, we went to Barcelona, Spain, to a workshop with the title **“Walking together towards the future”** where all members could join ideas about the path forward for Cochlear Implant Users.



MEMBERSHIPS AND COOPERATIONS

THE PLATFORM

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.

Further information: info@epdhdb.eu or please visit the website: www.epdhdb.eu

Follow the Platform: @EPDHDB



European Platform of Deafness, Hard of Hearing, and Deafblindness

About us
In May 26th 2012, the "European Platform of Deafness, Hard of Hearing and Deafblindness" was created in Copenhagen during the General Assembly of the European Disability Forum, EDF.

The Platform has been formed to enhance, strengthen and cultivate a robust and enduring collaboration between the organizations representing the deafness, hard of hearing and deafblindness regardless of the language, the communication system or the assistive technologies (hearing aids and cochlear implants).

www.epdhdb.eu @EPDHDB
All members of the Platform are also members of the Disability Forum.
Nothing About Us Without Us

We aim
Eliminate barriers to information and communication
ACCESSIBILITY in all areas of life:

Education Transport
Media Culture
Health Leisure Emergence
Labour Social Security
Transport



Representatives of the Platform members meet a few times a year to work together to eliminate barriers to communication & push for accessibility as well as strengthen their relationships.

Platform Members



EURO-CIU
European Cochlear Implant Users
EURO-CIU is a European network of people with cochlear implants who share their experiences and knowledge to improve the lives of others with cochlear implants.

EDbN
European Deafblind Network
EDbN is a European network of people who are deafblind or have a combination of hearing and vision impairment. EDbN aims to improve the lives of its members by providing information and support.

EFHOH
European Federation of Hard of Hearing People
EFHOH is a European network of people who are hard of hearing. EFHOH aims to improve the lives of its members by providing information and support.

FEPEDA
European Federation of Parents of Hearing Impaired Children
FEPEDA is a European network of parents of children who are hearing impaired. FEPEDA aims to improve the lives of its members by providing information and support.

EUD
European Union of the Deaf
EUD is a European network of people who are deaf. EUD aims to improve the lives of its members by providing information and support.

IFHOHYP
International Federation of Hearing Impaired Young People
IFHOHYP is a European network of young people who are hearing impaired. IFHOHYP aims to improve the lives of its members by providing information and support.

EUROPEAN FRIENDSHIP WEEK

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 2018 more than 65 participants from all over Europe enjoyed European Friendship Week, that since 2016, has the OUTSTANDING in all areas award, after being inspected by UK Ofsted.

“ It makes you more open to learn about others and yourself.



ACT!

SEMINAR ACCESSIBILITY COMMUNICATION TODAY

On February 20th 2018, EURO-CIU, the European cochlear implant users association, organized together with members of the Deafness Platform, the hearing impaired and the deafblind, an event to promote and fight for more accessibility to communication in all products and services. The seminar called ACT! (Accessibility Communication Today!) took place at the headquarters in Brussels of Microsoft, a company that is currently working on making its products more accessible as it is very sensitive to issues of disability and deafness in particular, having one of its directors, deaf herself; and having created a position within the company that is dedicated to promoting accessibility inside and outside the company, called accessibility evangelist.

Together with Microsoft, managed to unite all stakeholders from the field of communication and information technologies, the disabled movement and the European institutions, with members of the European Parliament and the European Commission, so that together we could discuss the accessible technology, the opportunities and challenges that face us in the future, as well as the legislative progress in this area. Several speakers were present: Emmanuelle Grange, the director of Disability and Inclusion of the European Commission; Helga Stevens, Member of the European Parliament and Jenny Lay-Flurrie, Director of Accessibility at Microsoft, as well as Immaculate Placencia Porrero, of the Social Affairs, Disability and Inclusion Unit of the European Commission, and followed by Alejandro Moledo, in charge of new technologies and innovation of the European Disability Forum.





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.

The European Disability Forum
is an independent NGO that
represents the interests of
80 million
Europeans with disabilities.

EURO-CIU supports EDF's campaigns in the European Union to achieve laws, regulations & directives that help persons with disabilities but specially persons with hearing loss users of a cochlear implant.

During 2018 EURO-CIU has lobbied for a "Strong Accessibility Act" as well as for "EU Elections accessible" that will be celebrated in May 2019.

Together, EURO-CIU and EDF are a strong, united voice of persons with disabilities in Europe. Further information: www.edf-feeph.org

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. Further information: www.who.int/pbd/deafness/world-hearing-day



Teresa Amat, President of EURO-CIU at the World Health Organization

WORLD HEARING FORUM

In September 2018, WHO will establish the World Hearing Forum, a global network of stakeholders promoting ear and hearing care worldwide. Members of this advocacy network will commit to facilitating implementation of World Health Assembly resolution WHA70.13 on “Prevention of deafness and hearing loss” and supporting Member States in this regard. Further information: www.who.int/deafness/world-hearing-forum/en/



CAMPAIGNS

EURO-CIU mission is to increase access to the gift of hearing provided by cochlear implantation through awareness and research and to fight at European & World level for a more accessible and inclusive society. For that reason during 2018 EURO-CIU has lobbied in several campaigns:

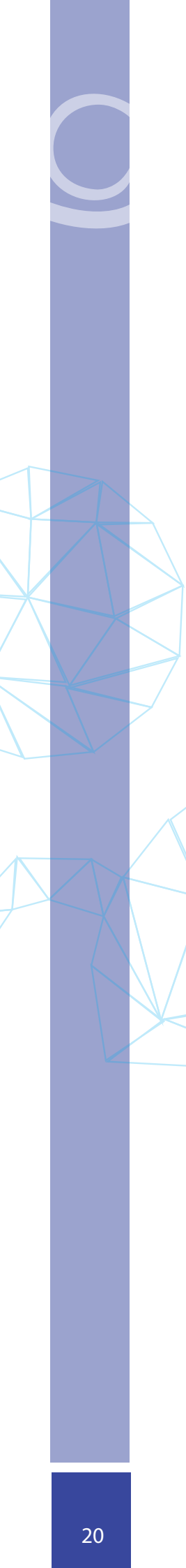
STRONG ACCESSIBILITY ACT

Thanks to the efforts of the last few years European Disability Forum (EDF) 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.

#Elections2019Accessible

#BreakCommunicationBarriers

During 2018 and until may 2019, EURO-CIU will lobby for accessible elections. 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!



EUROPEAN DISABILITY DAY

EURO-CIU is a participant to the European Disability Day organized by the European Commission for the last 5 years thanks to the lobby work EURO-CIU is doing. This December 2018, our vice president, Sari Hirvonen-Skarbö, a cochlear implant herself, exposed several of our claims & grievances, fighting for a more accessible society in the European Union that includes all disabilities, especially the cochlear implant users.

EU ELECTIONS ACCESSIBLE

We must ask Europe administrations and politicians to stand by their words of support to disability and uphold our rights as #WeAreCitizens and vote too!

For that reason, EURO-CIU has sent a letter to members of the parliament & candidates to ask for EU accessible elections for cochlear implant users; and together with the Platform, we have sent a similar letter asking for accessible elections with all the hearing loss, deaf & deafblind demands together. During 2018 and until May 2019, EURO-CIU will lobby for accessible elections, and after that, EURO-CIU will present themselves to all new MEPs and ask them to think about cochlear implant users when they legislate for the next years.

SPEND 2 SAVE

Spend2Save Campaign: a growing community of action in 2018!

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

The Spend2Save Campaign grew out of the work by The Ear Foundation in the UK on the Real Cost of hearing loss: showing that the cost of NOT managing hearing loss well is greater than the cost of providing hearing care. The full Spend2Save report was launched by The Ear Foundation in Brussels in September 2016 with EURO-CIU, AEA, EHIMA, EFHOH and with the support of Shelly Chadha of WHO and of our industry partners.

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.

The key message for Spend2Save remains:

- Hearing loss has a huge, unseen impact whether in children or adults
- It's a growing societal issue, recognised by the World Health Organisation
- Today's hearing aids, cochlear and other implants and communication technologies can change this
- Managing hearing loss well saves society money; the evidence is there and growing....
- And changes lives!

52 million people across Europe have hearing loss and the number is growing..... (EFHOH, 2016,2018; AEA 2017; EHIMA 2017) and the global costs to society are estimated as \$750 million per year (WHO, 2016).

Spend2Save: second edition!

Updating the document is fast and easy – giving user and advocacy groups access to updated facts and figures and peer reviewed papers to support their discussions. So.... a major achievement of 2018 has been the Second Edition by Sue Archbold and Brian Lamb for The Ear Foundation – and with the continued support of EFHOH, EHIMA, AEA and EURO-CIU. The second edition includes many more recent paper supporting increased investment in hearing care and also refers to the increasing WHO work on Sound Investment, and the agreement of their resolution.



HEARING LOSS AWARENESS

EURO-CIU collaborated as well with the Austrian Presidency, specially MEP Heinz Becker, during 2018 to raise awareness about hearing loss and the need to invest in technologies like hearing aids & cochlear implants, as it will reduce the future cost in health care, following Spend2Save campaign.

33. SPAR MARATHON

It was the first in the life of the EURO-CIU that we campaigning at a sport event. A small but enthusiastic team stood to the start line of the 33. International Spar Marathon and successfully completed the challenge.

In the future we would like to attend similar running competition in various European cities and raise awareness.



MEMBERSHIP

EURO-CIU has 31 full members from 23 European countries and 6 corresponding members.

Full members from A to Z



Austria - Cochlea Implantat Austria (CIA)

cia@liwest.at, k-h.fuchs@liwest.at, www.ci-a.at



Austria - Österreichische Cochlear Implant Gesellschaft (ÖCIG)

info@oecig.at, www.oecig.at



Belgium - Association de Parents d'Enfants Déficients Auditifs

Francophones (APEDAF)

info@apedaf.be, www.apedaf.be



Belgium - Vlaamse Ouders van Kinderen met Cochleaire Implant (VLOK-CI)

voorzitter@vlok-ci.eu, www.vlok-ci.eu

Bosnia and Herzegovina - Udruženje za podršku djeci s teškoćama sluha i govora (EHO)

fb.com/eho.sarajevo/, eho.sarajevo@gmail.com



Cyprus - ΠΑΓΚΥΠΡΙΟΣ ΣΥΝΔΕΣΜΟΣ ΓΟΝΕΩΝ ΠΑΙΔΙΩΝ ΜΕ ΑΠΩΛΕΙΑ ΑΚΟΗΣ

syndesmoskofon@cytanet.com.cy, www.childhearingloss.org.cy



Czech Republic - Sdružení Uživatelů Kochleárního Implantátu (SUKI)

info@suki.cz, www.suki.cz



Denmark - Cochlear Implant Foreningen (CIF)

formand@cochlearimplant.dk, www.cochlearimplant.dk



Denmark - Familieforeningen for Cochlear Implanterede Børn (deCibel)

tanja@decibel.dk, https://decibel.dk/



Denmark - Høreforeningen

mail@hoeforeningen.dk, www.hoeforeningen



Estonia - Eesti Implantsaadilaste Selts (Implantaadilaste)

selts@implantaadilapsed.ee, www.implantaadilapsed.ee



Finland - The Finnish Federation of the Hard of Hearing (FFHOF)

www.kuuloliitto.fi



Finland - Sisäkorvaistutusten valtakunnallinen yhdistys (LapCI)

info@lapci.fi, www.lapci.fi



France - Cochlée France (Cochlée France)

afiac.france@gmail.com, afiac.fr



**France - Association Française des Implantés Auditifs Cochléaires
Sourds Appareillés (AFIAC)**

gilles.cognat@free.fr, www.cochleefrance.fr



Germany - Deutsche Cochlea Implantat Gesellschaft (DCIG e. V.)

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Hungary - Magyar Cochleáris Implantáltak Egyesülete (MACIE)

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Italy - Associazione Genitori ed Utenti Audiovestibologia Varese onlus (AGUAV)

segreteria.fav@gmail.com, www.aguav.it



Luxembourg - Lëtzebuerger Associatioun vun de Cochlear Implantéierten (LACI)

laci@iha.lu, www.laci.lu



The Netherlands - Onafhankelijke Platform Cochleaire Implantatie (OPCI)

info@opciweb.nl, www.opciweb.nl



Poland - Stowarzyszenie Słyszeć bez granic (SSBG)

slyszecbezgranic@ slyszecbezgranic.pl, www.slyszecbezgranic.pl,
fb.com/slyszecbezgranic



Portugal - Associação Portuguesa de Portadores de Próteses e Implantes Auditivos (Ouvir)

ouvir.apppia@gmail.com, ww.ouvir.pt, fb.com/associacao.ouvir



Romania - Asociația națională a persoanelor cu deficiențe de auz "Asculță Viața!" (Asculță Viața)

www.ascultaviata.ro, asociatiaascultaviata@gmail.com



Serbia - Kohlear Implant Info Udruženje (KiS)

udruzenje.cii@gmail.com, www.kohlearniimplantinfo.com



Slovakia - Združenie užívateľov kochleárneho implantátu (ZUKI)

ivana.salinkova@ksutn.sk, www.scki.sk



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)

info@barnplantorna.se, www.barnplantorna.se



Sweden - Hörselskadades Riksförbund (HRF)

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Turkey - Cochlear Implant Derneği (CID)

koklearder@hotmail.com, www.koklearimplantdernegi.org.tr



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



The Ear Foundation



Prof. Ernst Lehnhardt-Foundation



Hear now. And always

Contact:

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