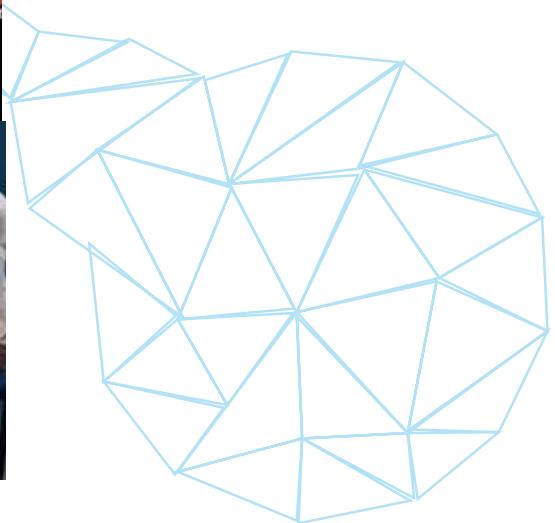


ANNUAL REPORT

2019

Acknowledgements:

Special thanks to Advanced Bionics, Cochlear, MED-EL and Oticon Medical for their continuing and generous support of EURO-CIU.



Euro-CIU Annual Report 2019

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PRESIDENT'S MESSAGE

In this report you can read about the major accomplishments of EURO-CIU during 2019. 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 Stowarzyszenie Słyszeć bez Granic (our polish member) in Wrocław, Poland. The huge turnout confirmed interest in updating all medical, technical, social and rehabilitation areas related to cochlear implants.

Once again we helped to empower young cochlear implant users by supporting European Friendship Week.

Regarding participation and collaboration with other entities, we are pleased to have continued with our active presence both in the Platform (EPDHD**b**) 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 Henri-François or I have made.

Perhaps the most spectacular leap has been the work that our scientific advisor, Leo de Raeve, has carried out in European and worldwide projects such as the MOSAICS project and CAPAC Study. Also, "Spend2Save" continues to advance and expand in the hands of Sue Archbold.

We are filled with pride to be recognized as members of Hear-it and the World Hearing Forum. It demonstrates that we have worked hard this year to achieve actions, proposals and documentation to obtain the relevant credentials. This would not have been possible without the work of Beatrice, our secretary, and Laia, our collaborator, whose tasks go far beyond being my assistant.

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.

We face 2020, EURO-CIU's 25th anniversary year, with the need to improve our presence in social networks and to give more voice to our youth. We must 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 amazing high-tech devices which enable profoundly and severely deaf people to hear. A CI system consists of two parts: an external processor which 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 a cochlear implant. 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.



EURO-CIU

EURO-CIU is a non-governmental, non-profit association, established in Luxembourg in 1995. The association brings together 33 national member associations from 25 European countries. Altogether EURO-CIU represents around 220,000 cochlear implant (CI) users across Europe, approximately 60% of whom are adults and 40% children.

EURO-CIU's mission is to increase access to the gift of hearing provided by cochlear implantation through awareness and research.

EURO-CIU Annual General Assembly: Wroclaw, Poland, 27th April 2019

The AGA was held with the representation of the 31 members of the European association and inaugurated by its President who thanked all the delegations of the associations and countries for their presence, especially the Polish Stowarzyszenie Słyszeć bez Granic Association (SSBG) for organizing the Symposium and the infrastructure for the Assembly.

There were a number of presentations:

- Leo de Raeve, scientific advisor of EURO-CIU, showed cochlear implant statistical data in Europe. He stressed the need to continue working especially for adult and older candidates.
- Sari Hirvonen-Skarbö, EURO-CIU Vice-President told how over 40 countries are joining in the International Day of Cochlear Implants.
- Laia Zamora, youth director of the AICE Federation, presented the results of a study on school bullying experienced by implant users in Spain. The rate of bullying doubles or triples when compared to the general population.
- The Ukrainian Association of Cochlear Implants presented its work and members, and has started the integration process into EURO-CIU.



EURO-CIU elections

In accordance with statutes, elections took place during the Annual General Meeting held by EURO-CIU in Wroclaw on 27th April 2019. The Treasurer and President were re-elected and Robert Mandara (British, living in Finland) became the new 1st Vice President. The board meets several times each year.

The board and advisors



Left to right: Sari Hirvonen-Skarbö (Finland), EDF representative, Leo De Raeve (Belgium), Scientific advisor, Ervin Bonecz (Hungary), 2nd Vice President, Beatrice Cusmai (Italy), Secretary, Henri-François Baiverlin (Belgium), Treasurer, Teresa Amat (Spain), President, Robert Mandara (Finland/UK), 1st Vice President, Brian Archbold (UK), Newsletter, Fernando Giménez (Spain), Website advisor.

OUR AIMS

1. Supporting adults and children with cochlear implants:

- a. We promote access to CI with costs covered by national healthcare systems.
- b. We demand that CI candidacy is based on the patient, not just on auditory thresholds.
- c. The decision to implant must be based on full informed consent of parties involved.
- d. Assistive hearing technologies made available as needed.
- e. Products, environments, programmes and services must be accessible to all.
- f. Stressing that cochlear implants are cost effective on any current cost benefit measure at any age, from babies to old age.
- g. All professionals supporting CI-users need to have up-to-date knowledge.

2. Specifically for children:

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

3. Raising awareness:

- a. We want to highlight the societal costs of untreated hearing loss.
- b. We advocate for hearing screening for all new-borns and adults from around age 55.
- c. Doctors and audiologists need better training about the potential benefits of CI to adults and older patients, as research confirms age-related hearing loss as a potential risk factor for cognitive decline, cognitive impairment, and dementia.
- d. Increase awareness of best CI practice amongst patients, families, health professionals, educators, policy-makers, funders and the general public.
- e. Encourage policy-makers and public health authorities to promote CI.
- f. Collaborate with other organizations to promote CI as the standard of care treatment within non-hearing loss disciplines.

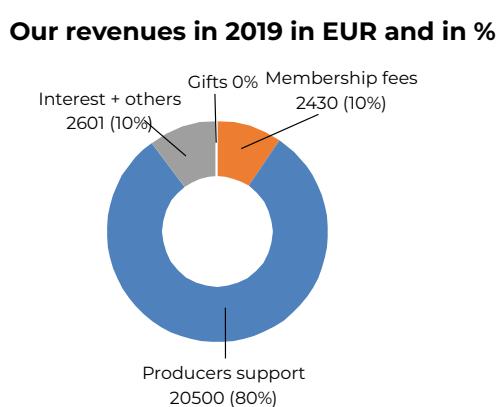
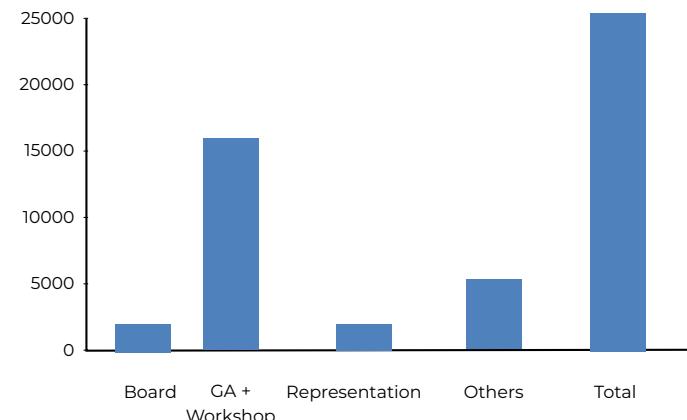
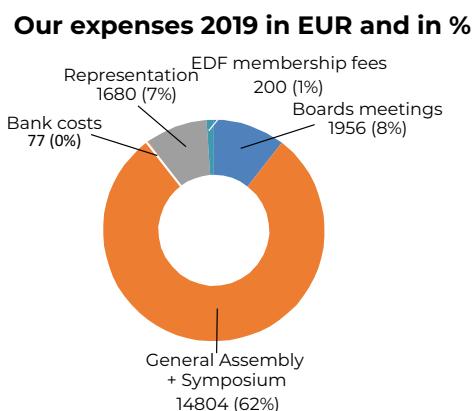
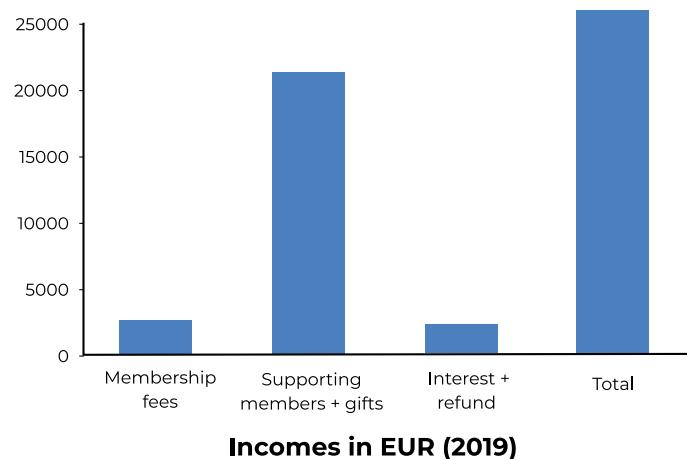
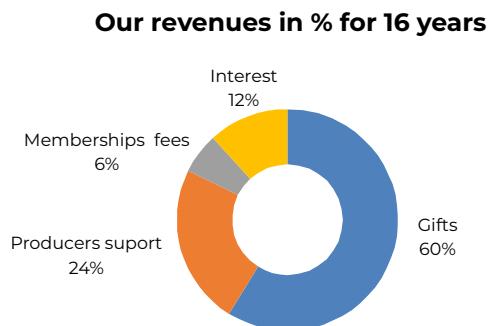
4. Research:

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

5. 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.

FINANCIAL SITUATION



COLLABORATIONS AND PROJECTS

EURO-CIU encourages and supports research into all aspects relating to cochlear implants, including the provision of rehabilitation to all CI users regardless of age.

Consumer and Professional Advocacy Committee (CAPAC) about Adult CI

On the 6th December 2019, hearing health professionals, consumer advocacy organizations and the four CI-companies (19 organisations representing 40 countries) attended a meeting of the Consumer and Professional Advocacy Committee (CAPAC) in Geneva. The purpose was to discuss and plan advocacy activities around the forthcoming publication of the Delphi Consensus on International Standards of Care for Adult Cochlear Implantation.

The aim was to improve worldwide access to and awareness of the benefits of cochlear implants (CI) to treat severe to profound sensorineural hearing loss.



The meeting attendees agreed that advocacy, education and awareness efforts should intensify to provide cochlear implant education to healthcare professionals, enabling diagnosis, and appropriate referral pathways to expert CI practitioners. They also stressed the need for worldwide recognition of the benefits of bilateral implantation for adults, and for improved standards for rehabilitation and aftercare. Adult hearing screening programs would help millions of adults with untreated hearing loss to hear.

To improve referrals pathways and treatment an International Delphi Consensus Process paper on a minimum Standard of Care for Adult CI treatment should be published in February 2020. An International Standard of Care will provide expert guidance on improved referral pathways and consistent clinical guidelines for treatment of severe to profound sensorineural hearing loss.

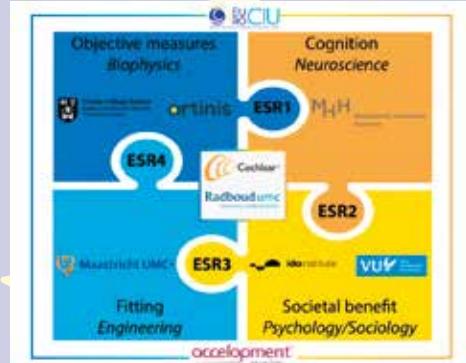


It was agreed to develop in the near future an International Cochlear Implant Advocacy Alliance (ICIAA), because cochlear implant advocacy is a longitudinal task. EURO-CIU can be an important partner in a developing International Cochlear Implant Advocacy Alliance, highlighting lack of access and raising awareness about the benefits of cochlear implants.

About the anticipated consensus paper on cochlear implants:

Craig Buchman, M.D., chair, steering committee of the Delphi Consensus Process on International Standards of Care for Adult Cochlear Implantation, and head of Otolaryngology-Head and Neck Surgery, Washington School of Medicine, United States, buchmanc@wustl.edu

MOSAICS European Industrial Doctorate project



MOSAICS is a European Industrial Doctorate project funded by the European Union's Horizon 2020 framework programme for research and innovation, that will train future experts and leaders in auditory implants to achieve minimized outcome spread and maximized participation in society (Grant agreement No860718).

The program is led by Cochlear Ltd and the Radboud Medical Centre in the Netherlands. EURO-CIU is a supporting partner.

Four Early Stage Researchers (ESRs) will be part of a multidisciplinary training programme, learning from the industrial excellence of a global hearing implant manufacturer and from the outstanding research expertise of the leaders in the field of hearing research. The specific objectives of MOSAICS are to:

- investigate the “body functions” by evaluating the neuronal activity following sound and speech stimuli at the level of the cochlea, the brain stem, and the cortex, using biophysics methods
- adopt an engineering approach and the aid of artificial intelligence (AI) to explore “environmental factors”, obtaining insight into the fitting issues related to outcome spread
- address the cognition (brain) effects on process-related outcome measures in relation to CI performance
- evaluate the societal benefits of CI-specific rehabilitation programmes and recipients’ social support

EURO-CIU will participate in network-wide training activities and guide the research training program as a member of the supervisory board. The ESRs are expected to present their findings in a future EURO-CIU Symposium.

For more information about the project see: <http://www.mosaics-eid.eu/>



Ignacio Calderon de Palma
Objective measures

Ignacio is a Sound Engineer and graduated at the Universidad Nacional de Tres de Febrero (Buenos Aires) in 2019.



Loes Beckers
Cognition

Loes holds a Research Master degree in Cognitive and Clinical neuroscience, focusing on cognitive neuroscience, obtained at Maastricht University (2019).



Nikki Tromp
Societal benefit

Nikki holds a Master of Science degree in Audiology, obtained at Cape Town in 2019.



Enrico Migliorini
Fitting Engineering

Enrico finished his Master's Degree in Computer Science, obtained at the University Politecnico di Milano, last year.

SPEND2SAVE

The Spend2Save Campaign grew out of the work done by Sue Archbold and Brian Lamb on behalf of 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 Organization.
- 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!

2019 saw the launch of the Second Edition by Sue Archbold and Brian Lamb for The Ear Foundation, with the continued support of EFHOH, EHIMA, AEA and EURO-CIU. It includes many more recent papers supporting increased investment in hearing care and also refers to the increasing WHO activity on Ear and Hearing Care. It is available in many languages from www.eurociu.eu or www.earfoundation.org.uk and has already been used with governments, in Sweden, Italy and Belgium.

In January 2019, EURO-CIU were represented in a meeting facilitated by Sue Archbold, bringing together advocacy groups from the Nordic countries to discuss how to move forward with improving access to CI for adults. Opportunities and challenges were shared, and the group agreed their priorities, wishing to meet again. Spend2Save (available from www.eurociu.eu in many languages) was widely used.



Beatrice Cusmai, EURO-CIU Secretary discussing Spend to Save with Emanuele Monti, President of III Permanent Commission, Health and Social Politics, Lombardy, Italy

SUMMARY

Spend2Save: Investing in hearing technology improves lives and saves society money

Adult Hearing Loss: Europe's growing challenge

Hearing loss is a major public health concern across Europe. Currently, the prevalence of the disease is reported to range from 5% to 15% of the population. In Europe, it is estimated that 52 million people have hearing loss. This report highlights the significant impact of hearing loss on individuals and society, and provides evidence for action. It calls for increased investment in hearing care, including research, development, and implementation of effective interventions. It also emphasizes the importance of early intervention and the need for better integration of hearing care into routine healthcare systems.

Investing in hearing technology improves lives and saves society money. The report shows that effective hearing interventions can reduce the risk of social isolation, improve quality of life, and reduce the economic burden of hearing loss. It also highlights the potential for hearing technology to contribute to economic growth and job creation.

Key findings include:

- 52 million people across Europe have hearing loss and the number is growing... (EFHOH, 2016, 2018; AEA 2017; EHIMA 2017)
- Hearing loss is a major public health concern across Europe. Currently, the prevalence of the disease is reported to range from 5% to 15% of the population.
- Those with hearing loss are at five times the risk of developing dementia as those with normal hearing. One in four adults with hearing loss may develop dementia by the age of 75.
- Mitigating hearing loss may account for up to 6% of preventable hospital admissions and 10% of preventable deaths in Europe.
- An estimated 10% of people with hearing loss are at risk of social isolation and associated mental health problems.
- Older people with hearing loss are at five times the risk of depression than those without hearing loss. This risk is also associated with a higher risk of major depression.
- Social isolation is often a leading cause of depression and other mental health problems. It can lead to social isolation, which in turn can lead to further depression and other mental health problems.
- People with hearing loss are more likely to experience social isolation and depression than those without hearing loss.
- Those with hearing loss have higher rates of unemployment and underemployment. (Source: 2010)

The Ear Foundation®

SAMENVATTING

Spend2Save: Investeren in hoortechnologie verbetert de kwaliteit van leven en bespaart de maatschappij veel geld

Gedownload bij volledig toegang: Een grote uitdaging voor Europa

Communicatie en gezondheid zijn belangrijke prioriteiten voor de Europese maatschappij. Daarom is het belangrijk dat we ons inzetten voor betere gehoorverzorging. Dit rapport toont aan dat goede gehoorverzorging een belangrijke rol speelt in het bevorderen van de kwaliteit van leven en het behouden van gezondheid. Het rapport toont ook aan dat goede gehoorverzorging een belangrijke rol speelt in het behouden van gezondheid en het voorkomen van gezondheidsproblemen.

De belangrijkste conclusie uit dit rapport is dat goede gehoorverzorging een essentiële factor is voor een gezond leven. Dit heeft verschillende voordeelen:

- 52 miljoen mensen in heel Europa hebben gehoorverlies en dit aantal zal zich nog verder vergroten. De kosten voor deze gehoorverlies zijn momenteel onbekend, maar kunnen hoog zijn.
- Grootte: 52 miljoen mensen in heel Europa hebben gehoorverlies.
- Risico: Mensen met gehoorverlies hebben een hoger risico op dementie dan mensen zonder gehoorverlies.

Door goede gehoorverzorging te bieden kunnen we de gezondheid van mensen met gehoorverlies verbeteren en de kosten voor gezondheidszorg verminderen. Dit is belangrijk voor de gezondheid van de maatschappij en voor de gezondheid van individuen.

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- Risico: Mensen met gehoorverlies hebben een hoger risico op dementie dan mensen zonder gehoorverlies.

The Ear Foundation®

EUROPEAN FRIENDSHIP WEEK

European Friendship Week (EFW) is an annual summer camp for European 11 - 16 year olds with cochlear implants, held in Boston Spa, England. It is sponsored by EURO-CIU and The Ear Foundation. Since 2016 EFW has been awarded the rating of "OUTSTANDING in all areas" by UK Ofsted. EFW helps youngsters to build self-confidence, enjoy peer support, make new international friends, improve team-working and problem-solving, and practice using English. EURO-CIU aims to inspire future CI leaders during EFW.

48 youngsters participated in July 2019. The week is staffed by teachers of the deaf, speech and language therapists, staff of The Ear Foundation and members of the EURO-CIU national associations. The leaders are all experienced in working with young deaf people or are deaf themselves. EURO-CIU's Vice-President, Robert Mandara attended for the second time. The country leaders work as a team, ensuring that everything runs smoothly.

The week consists of a wide range of sports, games, crafts and activities, as well as day trips into Yorkshire. There is something for everyone. Highlights were visits to Leeds Art Gallery, Harewood House and Bolton Abbey, a steam train ride and watching cricket at Headingley Cricket Ground,





Every youngster makes a presentation in English about themselves and their country, and distributes national treats such as chocolates, sweets and salmon. Their confidence is amazing and it's wonderful to see how some of the more reserved youngsters suddenly command attention once they have a microphone in their hands. It is great to witness how intelligent, well-adjusted, well-behaved and articulate all of the youngsters are – with due credit to the miracle of cochlear implants.



INTERNATIONAL CI DAY

25/02/2019

Our numbers are growing
and we have the same PASSION:
we like to HEAR.
COCHLEAR IMPLANTS make it POSSIBLE.



February 25th is International Cochlear Implant Day. On that day in 1957 two French doctors, Andre Djourno and Charles Eyries, first electrically stimulated the auditory nerve with an electrode. In 2019 we celebrated the 62nd anniversary of this milestone with a special banner which was shared all around the globe.

CI day helps to raise awareness of and celebrate our appreciation for **#hearing, #rehabilitation, #CochlearImplants, #HearingAids** and **#SafeListening**, because all of us: **#WeLikeToHear!**

Join in with: **#CIDay #CochlearImplantDay**

The collage includes:

- Advanced Bionics:** ¡Feliz Día Internacional del IMPLANTE COCLEAR! (Happy International Cochlear Implant Day)
- EUCIU:** INTERNATIONAL CI DAY 25/02/2019 (Felicidades para todos los que tienen implantes cocleares, más aprecio va a seguir).
- Cochlear Europe, Middle East & Africa:** 25 febrero es el Día internacional del Implante coclear. Nuestro Dr. presidente de avanzada de la audición, Dr. André Djourno, realizó la primera estimulación eléctrica en el nervio auditivo en 1957.
- MED-EL:** Happy #InternationalCochlearImplantDay from 7-year-old Luca from Hungary! #cochlearimplants #hearingloss
- Oticon Medical:** Happy International Cochlear Implant Day!
- International CI Day 25/02/2019:** We zijn niet alleen meer en harder te horen dan ooit, maar we horen graag. Dat is mogelijk dankzij het Cochlear Implantat.
- 25/02/19 DÍA INTERNACIONAL DEL IMPLANTE COCLEAR:** DIA DEL IMPLANTE COCLEAR
- Happy international Cochlear Implant Day!**
- I ❤ MY COCHLEAR IMPLANT:** I ❤ MY COCHLEAR IMPLANT
- INTERNATIONAL CI DAY 25/02/2019:** MEITÄ OI YHÄ ENEMMÄN ME TÄYTTÄVÄN LÄHIMÄN PÄÄMÄÄRÄ HUOMAAMO KUULLAAN.
- 25/02/19 DÍA INTERNACIONAL DEL IMPLANTE COCLEAR:** DIA INTERNACIONAL DEL IMPLANTE COCLEAR
- CI – the sky is the limit:** Cochlear Implant Day, Feb. 25th 2019 #cochlearimplantday
- TÜRKİYEDE İKİ YILAR KOKLEAR İMPPLANT İLE DÜYUFSEYİZ:** 25 ŞUBAT LÜSLAR ARASI KOKLEAR İMPPLANT GÜNÜNZ KUTLU OLSUN
- INTERNATIONAL CI DAY 25/02/2019:** İyiyapı en iyiyapı, her zaman en iyiyapı.

SYMPORIUM – WORKSHOP

One of our main objectives is to organise events where we can learn from each other as well as support the country member which hosts the event. Each year we alternate between Symposums and Workshops in different parts of Europe. For previous events, please see our website.

EURO-CIU Symposium: Wroclaw, Poland, 25th – 26th April 2019

Representatives from 31 countries, around 200 people from all over the world, participated in the 12th EURO-CIU Symposium with the theme "Needs of users of cochlear implants in the modern world". After the inauguration by the president of the Polish association hosting the event, Adrian Szatkowski, and opening speech by EURO-CIU president, Teresa Amat, came a variety of conferences and panel discussions.

A wide range of topics were discussed, including:

- When CI should and shouldn't be considered.
- The ideal age or weight at which to implant babies.
- Considering if rehabilitation should begin even before implantation.
- Can a person be too old for cochlear implantation?
- Raising awareness that only 3% of adults who need a cochlear implant receive one.
- The launch of The Ear Foundation's briefing paper concerning hearing care, cognitive decline and dementia (download a copy from www.eurociu.eu).
- The advantages of bilateral implantation and reducing the interval between operations.
- Better interaction between programmers and speech therapists.
- The perils of re-implantation while an implant is still working.



BRIEFING PAPER

Hearing Care, cognitive decline and dementia: A public health challenge, or an opportunity for healthy ageing?

Brian Lubin OBE and Sue Archbold PhD



www.earfoundation.org.uk

The Ear Foundation®



- Patient expectations, in terms of rehabilitation, technology and personal control.
- Wide-ranging experiences and emotions at activation, both good and bad.
- Rehabilitation and support to promote successful outcomes, education and employment.
- Implant users in the labour market – a panel discussion with employers and employees.

Attendees enjoyed beautiful and moving musical performances in the breaks from cochlear implant users.

The event was accessible with speech-to-text provided, together with translations in multiple languages. This allowed persons from all over continental Europe, some with hearing loss, to exchange best practices and ideas.

The EURO-CIU Symposium is a meeting point to learn from each other, to improve; a place to relate to share and exchange; to be stronger and to be more visible.



EURO-CIU is a member of...

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

The World Health Organization (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. In cases 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.

EURO-CIU is proud to have become a member of the World Hearing Forum (WHF) hosted by the World Health Organization and established in September 2018. EURO-CIU's membership is effective as of September 2019 and we have been invited to be part of the Safe Listening Working Group.

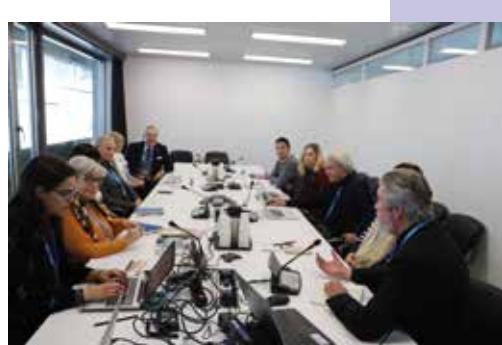


The WHF envisions a world in which no person experiences hearing loss due to preventable causes and those with hearing loss can achieve their full potential through rehabilitation, education and empowerment.

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 will work hard to rise to this new challenge and hopefully engage its members to follow suit. Cochlear Implant Users must become leaders of the hearing movement.

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

Hear-it

On the 17th October 2019, the Executive Board of Hear-it unanimously decided to recommend EURO-CIU as a member of their General Assembly.

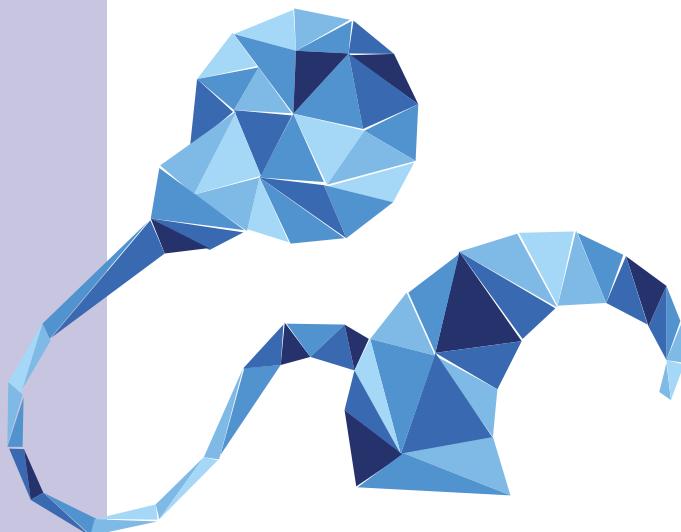


Hear-it AISBL is an international non-profit and non-commercial organisation that has been established to increase public awareness of hearing loss. The objective is to collect, process and circulate up-to-date scientific (sociological, legal, medical, public, policy related) and other relevant information including personal stories pertaining to hearing impairments and their human and socio-economic consequences.

The activities include cooperation with national organisations, dialogue with public authorities and others regarding issues on hearing impairments, and publishing www.hear-it.org in English, German, Spanish, French and Portuguese.

Hear-it AISBL deals with almost any issue related to hearing impairment, including:

- prevention of hearing loss
- the consequences of hearing impairment for the individual and society
- advice and practical information for hearing-impaired people
- information and advice for relatives and colleagues
- factual information about hearing issues
- statistics about hearing loss



The members Hear-it AISBL include The International Federation of the Hard Of Hearing (IFHOH), European Federation of Hard of Hearing People (EFHOH), EURO-CIU, European Association of Hearing Aid Professionals (AEA), individual members from the hearing aid industry, dispensers of hearing aids and others who share the objectives of Hear-it AISBL.

As most of their objectives are shared with EURO-CIU, we are very happy join HEAR-IT.



European Disability Forum (EDF)

“Nothing about us without us.”

The European Disability Forum is an independent NGO that represents the interests of 100 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 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. Accessibility ensures that all persons with disabilities, of any age or background, can live independently, move freely, work, shop, study and participate in leisure activities everywhere. 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.

Persons with disabilities cannot fully exercise their rights due to insufficient accessibility. We need to take action to ensure that the EU Member States adopt legislative measures to ensure the right to accessibility. The growing number of older persons in the EU means that many more people will benefit.

The European Accessibility Act goes some way to advancing the accessibility of products and services in the Single Market, but it does not effectively address accessibility to transport and the built environment. Therefore, an EDF resolution, calling for full accessibility of transport and built environment in the EU, was adopted by the Board of Directors of EDF in Helsinki, Finland in November 2019.



Further information:

<http://www.edf-feph.org/newsroom/news/edf-resolution-calling-full-accessibility-transport-and-built-environment-eu>

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

Further information: www.edf-feph.org

European Platform of Deafness, Hard of Hearing, and Deafblindness (EPDHD**b**)

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

The platform has been 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. The platform aims to strengthen the EU 2020 strategy and the EU Disability Strategy, to permit full and equal participation in society with the main aim of achieving a society without Communication Barriers. Representatives from each organization meet a few times a year.

EURO-CIU called upon the EU institutions and Members of European Parliament to make the European Elections of April 2019 inclusive and accessible, so that persons with disabilities could exercise their rights to vote or be elected. EURO-CIU called for subtitling, interpreters, real time captioning and induction loops so that everyone can be fully informed.

Further information:
info@epdhdb.eu [@EPDHD**b**](http://www.epdhdb.eu)



Platform Members

A grid of logos for the eight platform members:

- EURO-CIU**: European Association of Cochlear Implant Users
- EDbN**: The European Deafblind Network (EDbN) represents the needs of deafblind individuals who are not able to represent themselves and the services throughout Europe www.edbn.org
- EDbU**: European Deafblind Union (EDbU) represents deafblind persons, themselves hand their voice for equal opportunities in an accessible and inclusive Europe www.edbu.eu
- EFHOH**: European Federation of Hard of Hearing People is an European NGO consisting of 10 hard of hearing organizations at European level and our aim is to support hard of hearing people live without barriers www.efcoh.org
- FEPEDA**: FEPEDA is a non-governmental umbrella organization set up to represent associations of parents and friends of deaf and hard of hearing children at a European level www.fepeda.eu
- EUD**: European Union of the Deaf (EUD) is a European Non-Governmental organization representing Deaf persons at European level www.eud-eu.org
- EUDY**: European Union of the Deaf Youth (EUDY) is a European non-profit making organization whose membership comprises of national associations of deaf young people in Europe www.eudy-eu.org
- IFHOHYP**: International Federation of Hard of Hearing Young People serves as a platform for cooperation and exchange of information between organizations of hard of hearing youth and to defend their interests www.ifohhyp.org



#ThisTimeImVoting
for
#ACCESSIBILITY

2019

EURO-CIU
EUROPEAN ASSOCIATION OF COCHLEAR IMPLANT USERS



EURO-CIU campaign asking for European
#accessible elections for #disabled persons

European Day of Persons with Disabilities

The European Day of Persons with Disabilities conference was held in Brussels on 28th-29th November 2019. EURO-CIU has participated in this event organized by the European Commission for the last six 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.



Teresa Amat and Sari Hirvonen-Skarbö, EURO-CIU
representative in EDF.



Further information:

<https://ec.europa.eu/social/main.jsp?langId=en&catId=88&eventsId=1487&furtherEvents=yes#navItem-1>

CONGRESSES

Grupo Iberoamericano de Implantes Cocleares y Ciencias Afines - GICCA

From 5th to 8th June 2019, the 8th GICCA (Congress of Cochlear Implants and Related Sciences) was held in Pamplona, Spain, and attended by 1,000 participants from 30 countries with more than 226 conferences, 24 workshops, 9 instruction courses and 4 special sessions. The Presidents were Manuel Marinque and Ángel Ramos. The congress was hosted with the approval of the Spanish Society of Otolaryngology and Head and Neck Surgery.



L-R: Teresa Amat, Amarilis Melendez, ORL from the Ministry of Health of Panama and Co-chair of the Safe Listening Group in the World Hearing Forum

It is the largest meeting place in the world for professionals related to hearing implants in Spanish-speaking countries. There were five rooms, two of which had simultaneous Spanish/English translation or vice-versa.

Topics included Unilateral Cochlear implants, strange cases of Internal Cochlear Implantation Pain in the absence of stimulation, and the combination of electrode guides with stem cells, presented in a study as a new frontier in the regenerative biology of the cochlea.

Five cochlear implant manufacturers were present: Advanced Bionics, Cochlear, MED-EL, Oticon Medical and also the Chinese Nurotron who presented a study of several cases in Spain.

AG Bell Global Listening and Spoken Language Symposium

The AG Bell Global Listening and Spoken Language Symposium took place in Madrid 30th June to 2nd July, 2019. This was the first time that AG Bell International has organised a symposium outside US.

The main goal of this year's symposium was to bring together leaders in the field, professionals, and friends from around the world to share and discuss what is new and ongoing in the field of Listening and Spoken Language. More than 350 participants from over 40 countries attended. EURO-CIU was well represented at the symposium by Teresa Amat, Ann-Charlotte Gyllenram, Monika Lehnhardt, Joan Zamora and Leo De Raeve.

Workshops covered many interesting topics: Assessing and Treating Spoken Language and Listening Deficits from Cochlea to Cortex, Mentoring: How to Build Positive Mentor/Mentee Relationships, Learning to Listen Sounds: The Art and The Science, Forming Partnerships Through Family-Centered LSL Strategies, Forget the Pictures and Start Playing, Conscious Discipline: Behavior Starts with the Brain, A to Z – Newborn Hearing Diagnostics (NBD) to Auditory Management Through Preschool,...

A research forum, The Impact of Hearing Loss on Childhood Development and Family Constellation, addressed factors affecting family involvement, as well as related recent evidence that allows professionals to make more specific recommendations to families in order to reach a desired LSL outcome.

World-renowned audiologists Dr. Carol Flexer and Dr. Jane Madell closed the symposium by presenting their lifelong learnings and expertise gained from their long careers in the LSL field.



L-R: Leo De Raeve, Monika Lehnhardt, Teresa Amat, Ann-Charlotte Gyllenram, Joan Zamora

Further information of the proceedings:

https://agbellsymposium.com/wp-content/uploads/2019/06/2019-ag-bell-research-forum_final.pdf

ÖCIG Symposium

The 7th ÖCIG Symposium was held in the Ankersaal in Vienna on 12th October 2019, with the theme “Growing up with the cochlear implant”. The event was supported by sign language and speech-to-text interpreters, together with an induction loop system. Advanced Bionics, Cochlear and MED-EL were all represented.

Markus Raab, ÖCIG President and Henri-François Baiverlin, EURO-CIU Treasurer introduced the symposium.

Wide-ranging topics included “From the beginning of CI care to today - what will the future bring?”, “From stethoscope to cochlear implant”, “Listening and reading comprehension in children with a cochlear implant.” and “Difficulty listening to noise and possible effects on mental health and the subjective well-being of young CI wearers - What do we know from the literature?”

The next ÖCIG Symposium will be held in Salzburg in 2021.



Henri-François Baiverlin, EURO-CIU Treasurer

European Symposium of Paediatric Cochlear Implantation - ESPCI

In October 2019, Professor Luminita Rădulescu was President of the 14th European Symposium of Paediatric Cochlear Implantation (ESPCI), held in Bucharest at the Parliament House.

The theme of the meeting was Holistic Approach of Cochlear Implanted Children, a step closer. Around 1,200 delegates from 49 countries attended for the three days.

A range of plenary and workshop sessions provided something for everyone. Keynote speeches by Andrej Krall (Outcome Variability: From Cochlear Anatomy to the Connectome Model), Teresa Ching (Improving Outcomes in CIs) and Sue Archbold (Paediatric Cochlear Implantation: 30 years and still learning) were given to the packed main auditorium. The Round Tables and Workshops led to much discussion.

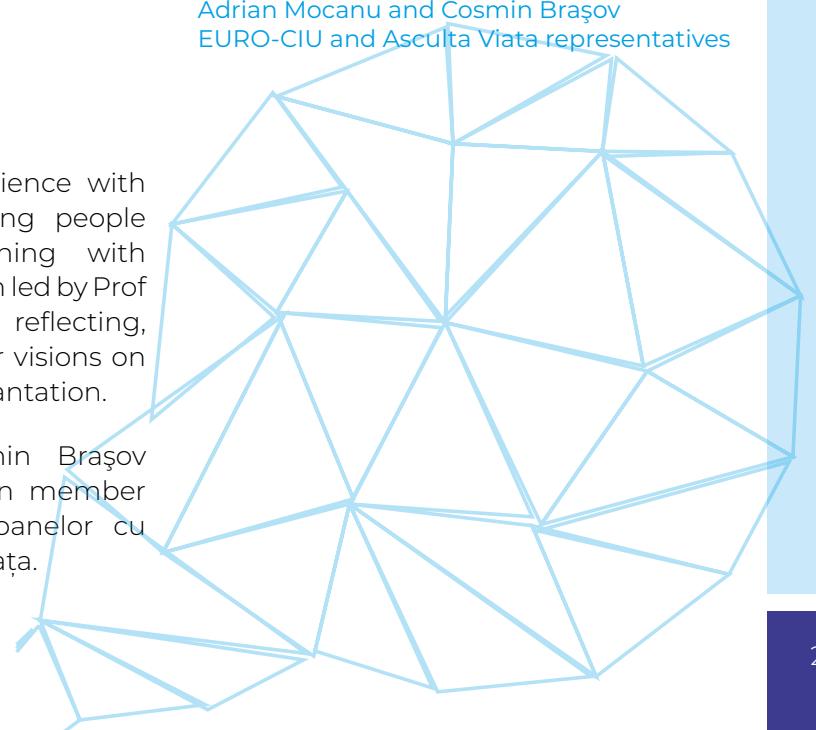


Prof. Dr. Luminita Radulescu ORL
from Romania and ESPCI 2019
Congress President

Adrian Mocanu and Cosmin Brașov
EURO-CIU and Asculta Viața-representatives

The conference combined the latest science with sessions provided by parents and young people themselves, including those entertaining with amazing music. It concluded with a session led by Prof Gerry O'Donoghue with Past Presidents reflecting, and Early Career Doctors presenting their visions on the complex issues facing paediatric implantation.

EURO-CIU was represented by Cosmin Brașov and Adrian Mocanu from our Romanian member association, Asociația Națională a Persoanelor cu Deficiențe de Auz din România Asculta Viața.



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. 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 on a new communication plan and opened a Facebook page. In 2018 we changed our logo and built a new website. Look us up and see all of the changes!

EURO-CIU Newsletter

The quarterly EURO-CIU Newsletter, delivered by email, has regular readers from all around the world, including politicians, senior directors from national and international organisations for the deaf, and important international bodies like the WHO.

Each Newsletter has articles supplied by our member organisations and supporters, which share news, ideas and best practice.

You will be joining over
2100 subscribers in
around 40 countries,
enjoying approximately
120 articles/year.



To subscribe for free,
email: newsletter@eurociu.eu



Our members participate by writing articles for our newsletter, telling us about best practices and news from all over Europe.



Social media



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



Our YouTube channel started in 2017 and now features a very nice video of our 2019 EURO-CIU Symposium in Wroclaw, Poland.
[https://www.youtube.com/ → EURO-CIU Social](https://www.youtube.com/ eurociu)



In 2019, our website had over 18,000 page views from 3,144 unique visitors. On International Cochlear Implant Day, 25th February, the site enjoyed the highest number of visitors, with 168 visitors and 350 pages downloaded. The four most popular pages are "What is the CI?", "Spend2Save 2nd Edition", "Membership" and "Newsletter".
www.eurociu.eu



Since starting in 2015, our Twitter presence has grown enormously. The highest amount of tweets were recorded in April, during the EURO-CIU Symposium and General Assembly in Wroclaw, Poland. We have more than 700 followers, and over 6000 tweets.
<https://www.twitter.com/Eurociu>
@eurociu

Tweet principal tuvo 2.738 impresiones

Make it visible! says @AlanaNichols #CochlearImplantUser about her #CochlearImplant. This helps with #representation & #RoleModels! We must make the invisible VISIBLE! Show your #CochlearImplants & #HearingAids! #WorldHearingForum #SafeListening #WorldHearingDay #HearingLoss pic.twitter.com/YI4jfLVrJr



129 8 18

DATOS DESTACADOS DEL TWEET

Tweet principal tuvo 1.058 impresiones

Nous avons le même passion.
#EntendrePlus

Avec l' #ImplantCochléaire c'est possible.
#CochlearImplantDay est le 25 février ! pic.twitter.com/rEMEse7HC8



4 1 423 5 17

Tweet principal tuvo 4.538 impresiones

are at @EDbN_org headquarters in in with their members sharing a bration with #deafblind persons & their lies. Happy to be here, specially on the #AccessibilityAct is approved by Uparliament. #accessibility Together eakingCommunicationBarriers! twitter.com/IUJUjUoiOrC



123 2 18 3

EURO-CIU Members

EURO-CIU has 33 full members from 25 European countries, plus five corresponding members.

Full members from A to Z:



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 Déficients 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: Høreforeningene
mail@hoeforeningerne.dk, <https://hoeforeningerne.dk>



Estonia: Eesti Implantaadilaste Selts
selts@implantaadilapsed.ee, epp.muil@neti.ee, www.implantaadilapsed.ee



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



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



France: Association Française des Implantés Auditifs Cochléaires & Sourds Appareillés (AFIAC & SA)
afiac.france@gmail.com, www.afiac.fr

COCHLEE FRANCE

France: COCHLEE FRANCE
gilles.cognat@free.fr



AURES

Deutsche Cochlea Implantat
Gesellschaft e.V.

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



Hungary: Magyar Cochleáris Implantáltak Egyesülete (MACIE)
info@macie.hu, www.macie.hu



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

COCHLEAKLUBBEN

Norway: Cochleaklubben
styret@cochleaklubben.no, www.cochleaklubben.no



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



Portugal: Associação Portuguesa de Portadores de Próteses e Implantes Auditivos
(Ouvir-APPPIA)
ouvir.appbia@gmail.com, www.facebook.com/associacao.ouvir



Romania: Asociația Națională a Persoanelor cu Deficiențe de Auz din România Asculță Viață
asociatiaascultaviata@gmail.com, [www.asculataviata.ro](http://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 Espña (Federación AICE)
j zamora@implantecoclear.org, www.implantecoclear.org

Barnplantorna

Klubbmedlen för barn med cochleaimplantat och barn med hörapparat

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



Prof. Ernst Lehnhardt-Foundation



The Ear Foundation



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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+34 933 317 475

twitter.com/eurociu

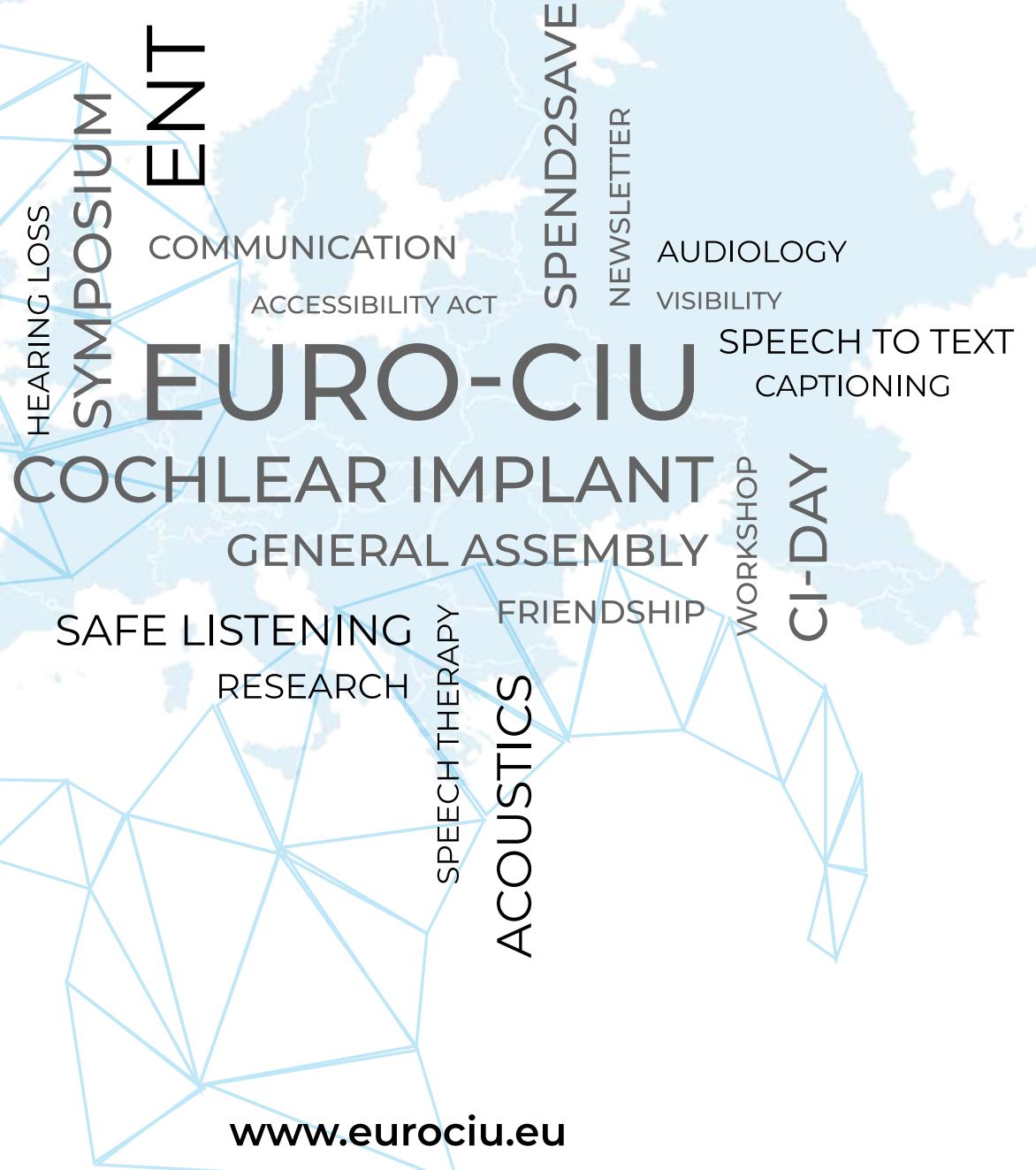
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info@eurociu.eu



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



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