

EURO-CIU

ANNUAL REPORT

2024



Acknowledgements:

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

EURO-CIU Annual Report 2024

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system or transmitted, in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, without prior permission.

EURO-CIU accepts no responsibility for any information that may be accessed from this report.

Designed and produced by EURO-CIU. Publication coordination: Tobias Fischer, Robert Mandara.

Text revision: Brian Archbold.

Table of Contents

President's Message	4
What are cochlear implants?	5
Who can benefit from cochlear implants?	5
EURO-CIU in brief	5
Visibility	6
International Cochlear Implant Day	6
CI2024 Las Palmas, Canary Islands	7
Stichting Plots & Laat Doven "Let's connect 2!"	8
Collaborations and projects	10
CIICA Advocacy in Action Conference	10
EURO-CIU	11
14th International EURO-CIU Symposium and General Assembly	11
EURO-CIU Summer Camp in Telč	12
Summer Camp in Telč – Report from a participant.....	14
EURO-CIU is member of	15
World Hearing Forum (WHF).....	15
European Disability Forum (EDF).....	16
EPDHDb	18
Financial situation	19
EURO-CIU Newsletter	20
Supporting Members	21
EURO-CIU Members	22

President's Message



You can read about the major accomplishments of EURO-CIU during 2024 in this report. For a more comprehensive record of events, please see our newsletters, website and social media.

EURO-CIU is increasingly influential and respected, so we are better able to make our voices heard by important stakeholders. Cochlear implants enable deaf people to hear and listen. Our national and European administrations are listening to us more and more.

We are proud to actively collaborate with and be active members of several other entities. With our member associations, we celebrated Cochlear Implant Day. We also participated in major congresses and conferences relevant to cochlear implants and hearing loss.

In April we held our own EURO-CIU Symposium in Vienna, Austria, hosted by CIA. Once again, we were delighted to see participation from young adult cochlear implant users. As the first generation of cochlear implant users become adults, it is vital that they become advocates for their generation.

In July, in conjunction with SUKI, we held the EURO-CIU Summer camp in Telč, Czech Republic. This was hugely successful and was a great opportunity to introduce young CI users to the situation of CI within Europe and to encourage them to become active advocates.

In December I was privileged to meet the great Professor Graeme Clark in Australia. He was very keen to emphasise the importance of EURO-CIU having a clear vision and of us collaborating more beyond Europe's geographical borders.

In 2025, with thanks to the efforts of all Presidents, Board members, Advisors, member associations, sponsors and other supporters, we look forward to celebrating 30 years of EURO-CIU. It is vitally important that we continue our work to improve awareness, access, rehabilitation and lifelong care. By working together, we can help many more people to hear and get the very best outcomes with cochlear implants.

Robert Mandara,

EURO-CIU President

What are cochlear implants?

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

Who can benefit from cochlear implants?

People with unilateral or bilateral severe or profound deafness (typically around 80 – 90 dB loss), who get little or no benefit from hearing aids, may be candidates for cochlear implants. The exact criteria used for implantation varies depending on the region. Candidates undergo a thorough assessment process at a cochlear implant centre.

EURO-CIU in brief

EURO-CIU is a non-governmental, non-profit association, established in Luxembourg in 1995. The association brings together national member CI user associations from across Europe. Altogether EURO-CIU represents the users of around 500,000 cochlear implants across Europe, approximately 60% of whom are adults and 40% children. Each year, around 25,000 European citizens receive cochlear implants. Globally, around one million cochlear implants are in use.

We aim to support cochlear implant candidates and users of all ages, raise awareness, encourage research and ensure that the world is accessible to CI users.



Visibility

International Cochlear Implant Day



February 25th, International Cochlear Implant Day, commemorates the groundbreaking surgery performed on this day in 1957 that paved the way for the development of cochlear implant technology. Celebrating its 67th anniversary, this day serves as a global reminder of the transformative power of cochlear implants in restoring hearing and enhancing lives.

As we honoured this milestone, EURO-CIU spearheaded awareness-raising events across Europe under the international motto: "We are united by a passion to hear".

Although there are over 500,000 cochlear implant recipients in Europe alone, there are still several million people who would benefit from cochlear implants, if only they had access to them. So, it's crucial that we continue to reaffirm our commitment to raising awareness, enhancing access, supporting rehabilitation, and ensuring lifelong care.

Cochlear implants represent an investment in individuals' quality of life. Studies suggest that the long-term benefits of cochlear implantation extend far beyond improved hearing, potentially delaying the onset of conditions like dementia and Alzheimer's. By investing in cochlear implants, societies invest in healthier, more inclusive communities.

Together, we celebrate the journey of sound and empower individuals to embrace life to the fullest.

CI2024 Las Palmas, Canary Islands



February 21st – 24th, EURO-CIU were exceptionally well represented at CI2024 the 17th International conference on cochlear implants and other implantable technologies. Three of our board members were present, as well as our scientific advisor and former President.

We participated in a panel session “Trends for families of cochlear implantees” and in two round table discussions, on “Ethics & Economics in CI” and on “Access of cochlear implants in adults: barriers and facilitators”. EURO-CIU challenged delegates to consider who upholds the rules of the CI game and who is setting the pace.

EURO-CIU had a stand where we were able to share information and make new connections.

Out of around 1500 delegates, we spotted only six cochlear implant users. Although this number is low, it is rare to have so much CI user visibility in this type of conference for medical professionals and researchers. We would certainly like to see more user advocates participating in future, to ensure that professionals, researchers and CI users are all working towards the same goals.

Stichting Plots & Laat Doven “Let’s connect 2!”

The Stichting Plots & Laat Doven “Let’s connect 2!” International congress was held 22nd – 24th March, in Egmond Aan Zee, The Netherlands. EURO-CIU President, Robert Mandara, gave a 1-hour presentation on CI advocacy challenges.

Around 100 people attended, and the majority were using hearing aids or cochlear implants. Attendees were mainly from The Netherlands, but some came from as far afield as the USA. The atmosphere was very warm, friendly and inclusive. Topics were generally focused on how to live and work healthily with deafness.

The congress was opened, in person, by Her Royal Highness Princess Petra Laurentien of the Netherlands. She has a genuine interest in hearing loss and made great suggestions for how delegates can advocate to help themselves. She reminded delegates not to play down the scale of the challenges they face.

A highlight of the congress was Brad Ingrao’s “Can we try that in Bb? Redefining your relationship with music after hearing loss” in which he explained in detail why some music is easier to interpret with CI than others.



Photos: on left a selection of photos from the Congress, on right Robert Mandara

HEARING HEALTH FORUM EU



EURO-CIU is a partner of the Hearing Health Forum EU (HHFEU), chaired by Alex Agius-Saliba MEP, who has a very keen interest in hearing loss and disability rights.

HHFEU's mission is to influence health policy and push for hearing screening in the European Union, so that people get appropriate treatments in a timely manner, so that they can enjoy healthier later years with, for example, potentially lower risks of dementia and isolation.

EURO-CIU is a supporter of HHFEU's Policy Manifesto on Hearing Health which calls on the European Commission to focus on raising awareness of hearing loss, ensuring effective early prevention strategies across the EU on a national level, improving access to appropriate hearing care and treatment and supporting research that facilitates evidence-based policymaking.

Prioritising hearing loss in health policy agendas will allow children and adults to reach their potential, Europe's elderly to actively age and ensure the long-term sustainability of our healthcare systems and society at large.

For more information, see: <https://www.hearinghealth.eu/>

Collaborations and projects

CIICA Advocacy in Action Conference



The first CIICA Advocacy in Action Conference took place 9th – 10th May 2024, in Brussels. Of the approximately 100 global attendees, over 35 were CI users. The conference was opened with a very special pre-recorded video message from Professor Graeme Clark. A very wide variety of excellent and powerful short presentations were made over the course of the two days. There was no time to get bored! EURO-CIU (Robert Mandara) made a presentation on “Ethics, Conductors and Arbiters”.

Delegates were moved by the panel of young adults with CI who share so many experiences and concerns although they have grown up in different countries. These young people are a testament to the transformative power of CI.



EURO-CIU collaborates closely with CIICA and has released joint briefing documents. To see events, resources and to join, see www.ciicanet.org

EURO-CIU

14th International EURO-CIU Symposium and General Assembly

The 14th International EURO-CIU Symposium and GA was hosted by Cochlea Implantat Austria (CIA) on 5th and 6th April respectively, at the Hauptbahnhof Novotel in Vienna.

Early arrivals were able to take a tour of The Josephinum Medical History Museum, led by Prof. Dr. Wolf-Dieter Baumgartner. The museum had a large exhibition related to hearing.

The Symposium “Steps on the way to hearing with cochlear implants” was attended by around 100 people.

A wide range of topics were covered, including screening, rehabilitation, music, Usher syndrome, patient associations, and what we can expect to see in the future. Three round tables were held, considering what rehab should include, the challenges faced by teens and young adults with CI, and the effect of CI on social life, employment and quality of life.

Following the well-attended and lively General Assembly, delegates enjoyed a fascinating 1-hour tour on an antique tram around Vienna, followed by dinner at Melker Stiftskeller restaurant.



EURO-CIU Summer Camp in Telč

The EURO-CIU Summer Camp was held 20th – 27th July, in the beautiful UNESCO World Heritage Site of Telč, Czech Republic. The camp was organised by SUKI, EURO-CIU's Czech member association. The Czech volunteers and participants made everyone feel welcome.



“I discovered a new world, so many things about cochlear implant users that I am still thrilled even only remembering them.”

The camp was full, with participants from nine countries who all got along very well. The priority was to have fun and to make international friends with CI-using peers. In at least one case, a participant had received implants as a baby but had never met another CI user before the camp. Everyone benefitted from meeting with their peers, both from their own countries and others.

Fun activities included hiking, swimming, making music, dancing, partying, visiting the adjacent castle, cooking sausages over a fire, sharing foods from different countries, a quiz and so much more. There was a lot of laughter.

“I immediately felt like we all could understand each other much better than our parents, because we wore the cochlear implant, so we knew how it feels to have one.”

“I met the rest of the Italian group at the airport, just before the flight, and I was surprised and pleased to meet those who now are my friends.”



**“The group was like a family,
something that never happened
to me.”**

Sessions were held to encourage the youngsters to think about CI advocacy, by considering and comparing the challenges that they face in their respective countries. Even today, there are huge differences in eligibility for CI, access to CI and funding.

The youngsters were also given the amazing and very important opportunity to better understand the hardware inside their heads, and the skills of the surgeons who installed that hardware. There was much amazement at how tiny the electrodes are, and how difficult they are to insert into surgeons’ training aids.

The youngsters arrived at the camp confident, but their confidence rose even higher over the course of the week.

**“Thanks to this experience I increased my
level of English.”**



Summer Camp in Telč – Report from a participant

When you have grown up amongst people who don't have a cochlear implant or hearing device, you almost think that you have normal hearing, but sometimes you have needs that normal hearing people do not understand. You don't think that there is the possibility that someone else could have your same feature, because you have never seen him or her before.

This summer, in Telč, I discovered a new world, so many things about cochlear implant users that I am still thrilled even only remembering them.

I met the rest of the Italian group (four teenagers and the leader) at the airport, just before the flight, and I was surprised and pleased to meet those who now are my friends. I immediately felt like we all could understand each other much better than our parents, because we wore the cochlear implant, so we knew how it feels to have one.

Once we arrived in Telč, in this beautiful university campus in the centre of the city, the first evening we did presentations of our countries, in which we explained something about it. With a special finale: after each presentation the guys of each group distributed a typical sweet or food, so that we experienced a gastronomic food exchange (when we shared the Sardinian typical guttiau bread, all people wanted more and more, especially the English ones).

During EURO-CIU summer camp, we did a lot of countryside walks and activities, and this made us get closer and closer, chatting with each other. Thanks to morning and afternoon activities organised during the day, I got to know the different groups – Bosnian, English, Romanian, Swedish, Luxembourgish and Czech. I found friends almost immediately. Sometimes I stayed with my group, but at a certain point I started to spend almost all the day with some foreign mates. I enjoyed the spirit of friendship among all participants that seemed to be linked by a special complicity.

The group was like a family, something that never happened to me.

Thanks to this experience I made new friends and I also increased my level of English. I would like to thank Marina, her gorgeous Czech organisation Suki and Robert, the president of EURO-CIU, who made all this possible. I really hope to take part in the next EURO-CIU summer camp. Thank you so much for what you've done for our cochlear implant community!



Vittoria Bianchi – AGUAV – Italy

EURO-CIU is member of World Hearing Forum (WHF)



EURO-CIU works with the WHF together to prevent hearing loss and draw attention towards the anticipated rise in the number of people with it across the world. Where hearing loss is unavoidable, we raise awareness to ensure access to appropriate and affordable assistive technologies such as hearing aids and cochlear implants.



In 2019 EURO-CIU became a member of the World Hearing Forum (WHF) hosted by the World Health Organization and established in 2018. EURO-CIU were invited to be part of the Safe Listening Working Group, with our previous EURO-CIU President, Teresa Amat, being Co-Chair of the Changemakers workstream.

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.

World Hearing Forum Members are part of a vast network of stakeholders working to address and promote ear and hearing care worldwide.

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

European Disability Forum (EDF)

The annual conference 2024 'European Day of Persons with Disabilities' took place in Brussels. The conference is part of the EU's wider efforts to raise awareness and tackle everyday challenges faced by persons with disabilities, in line with the UN Convention on the Rights of Persons with Disabilities and the EDF Strategy for the rights of persons with disabilities 2021-2030.



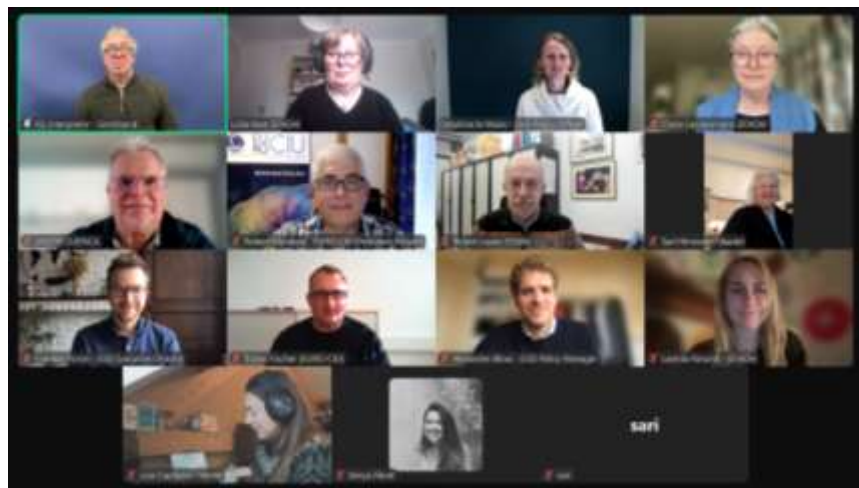
These two days of thought-provoking and engaging debate brought together people from a wide range of backgrounds with different expertise and stories to share, including policymakers, high-level experts, representatives from several institutions and disability advocates. EURO-CIU President Robert Mandara and EURO-CIU advisor and EDF Board member Sari Hirvonen-Skarbö were able to focus on networking and sharing information. The conference presented an opportunity to have an in-depth forward-looking discussion on the strategic objectives, policy proposals, and initiatives for the next five years.

Following tradition, the conference included the ceremony of the Access City Award contest and celebration of its 15th anniversary. The winners were cities from Austria Wien, Germany Nurnberg, Spain Cartagena, and Sweden Borås.

On International Disability Day, EDF sent an open letter from one hundred disability organizations, including EURO-CIU, to Commissioner Hadja Lahbib, European Commissioner for Equality: Preparedness and Crisis Management. Together, EDF urged her to commit to advancing disability rights by updating the EU Disability Rights Strategy.



At the beginning of November, the European Disability Forum Board met in Madrid. Sari Hirvonen-Skarbö, EURO-CIU advisor and EDF delegate, attended on behalf of EURO-CIU. Amongst other topics, the board discussed the need to include a disability perspective in disaster risk reduction and preparedness plans, and the ongoing draft of the EDF Strategy 2025-2030 “Nothing about us without us – Joining forces for a disability-inclusive Europe”, which will be launched in 2025. The strategy is divided into eight chapters that cover different areas where the EU aims to improve the lives of persons with disabilities.

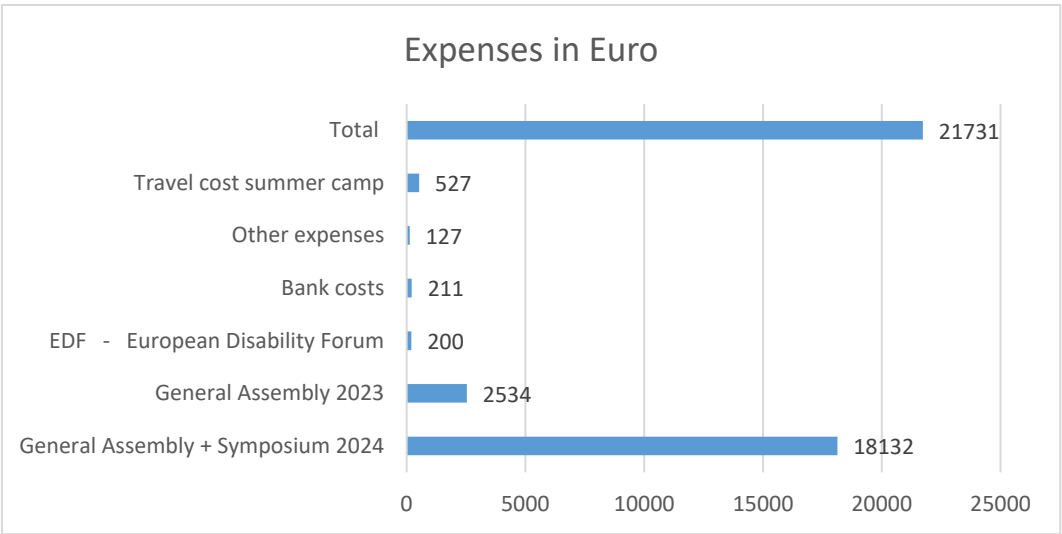
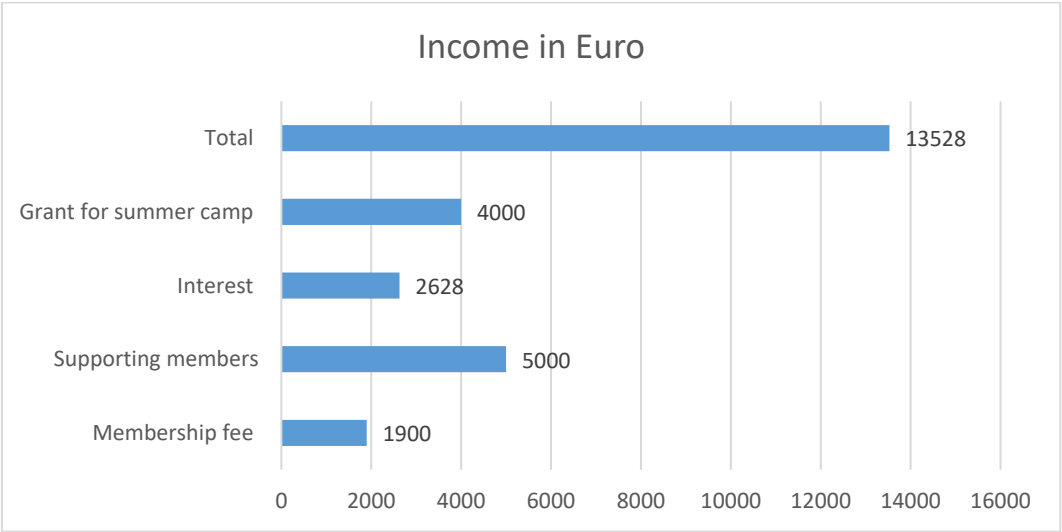


The European Platform of Deafness, Hard of Hearing and Deafblindness (EPDHDb) was created during the General Assembly of the European Disability Forum in 2012 to enhance, strengthen and cultivate a robust and enduring collaboration between eight organisations: EURO-CIU, The European Deafblind Network (EDBN), The European Deafblind Union (EDBU), The European Federation of Hard of Hearing People (EFHOH), The European Federation of Parents of Hearing Impaired Children (FEPEDA), The European Union of the Deaf (EUD), The European Union of the Deaf Youth, and The International Federation of Hard of Hearing Young People.

The purpose is to benefit all deaf people and their families, regardless of the language, communication methods or hearing instruments they use. Representatives from each organization meet a few times a year.

Further information: info@epdhdb.eu, www.epdhdb.eu, [@EPDHDb](https://www.facebook.com/EPDHDb)

Financial situation



The financial year is from 01.01.2024 to 31.12.2024.

Income in Euro

Membership fee	1900
Supporting members	5000
Interest	2628
Grant for summer camp	4000
Total	13528

Expenses in Euro

General Assembly + Symposium 2024	18132
General Assembly 2023	2534
EDF - European Disability Forum	200
Bank costs	211
Other expenses	127
Travel cost summer camp	527
Total	21731

EURO-CIU Newsletter

Brian Archbold is Editor of our newsletter which is produced four times per year – March, June, September and December – and, occasionally, special editions. Our Editor holds a



secure database under the General Data Protection Regulation (GDPR). We hold only the e-mail addresses of those who have indicated that they would like to receive the newsletter and related e-mails from us. At the end of 2024, there were 1,107 subscribers on our database. Many recipients share and forward the newsletters, so the average readership over the four issues in 2024 averaged over 1,800. The newsletter is read by professionals and manufacturers, many international organisations in the field of deafness and Members of Parliament (both in individual countries and in the European Parliament). In 2024, over 30 different

countries received our newsletter. We have readers not only in Europe but also in the Middle and Far East, the Americas, Australasia and the Indian subcontinent. Each newsletter has an average of 37 articles. Articles include information about EURO-CIU, other organisations with whom we work, member organisations and other organisations worldwide. The cochlear implant companies give us updates, and we are most grateful for their helpful and interesting insights. If you know of anyone who would like to receive our newsletter for free, they can contact Brian at newsletter@eurociu.eu. Previous issues can be seen here: <http://eurociu.eu/newsletter>

Social Media

Our primary goal is to provide support to individuals who are deaf, specifically those who use cochlear implants, irrespective of their age, the cause of their deafness, their country of origin, communication method, or social background. Through our efforts, we aim to raise awareness in society regarding cochlear implantation, communication barriers, and sensory disabilities. To achieve this, we disseminate information through our Newsletter, maintain an informative website, and stay connected with our audience through X (formerly Twitter), Facebook, and YouTube.

You can find us on social media platforms at the following links:



<https://www.facebook.com/eurociu/>



www.youtube.com/@eurociu



<https://www.x.com/Eurociu>



www.eurociu.eu

Supporting Members



MED⁹EL



Lehnhardt Stiftung

EURO-CIU Members

Full members in alphabetical order of countries:



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 Cochlea-Implantat-Gesellschaft (ÖCIG) / Austrian Cochlear Implant Society
info@oecig.at, www.oecig.at



Belgium : Association de Parents d'Enfants Déficients Auditifs Francophones (APEDAF a.s.b.l.)
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: ECHO Association for support to children / persons with hearing and speech disabilities
eho.sarajevo@gmail.com, www.facebook.com/eho.sarajevo/



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



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



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



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



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

COCHLEE FRANCE

France : COCHLEE FRANCE
gilles.cognat@free.fr



Georgia: Aures Foundation
auresfoundation@gmail.com [facebook.com/auresfoundation/](https://www.facebook.com/auresfoundation/)
x.com/Auresfoundation



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



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



Luxembourg: Lëtzebuerger Associatioun vun de Cochlear Implantéierten a.s.b.l. (LACI a.s.b.l.)
laci@iha.lu, www.laci.lu



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



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



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



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



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



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



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



Türkiye: Biyonik Kulaklı Çocuklar Derneği
biyonik.der@gmail.com, www.biyonikder.org.tr



Türkiye: Cochlear İmplant Derneği
filiz.aslan@koklearimplantdernegi.org.tr, 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

Contact:

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

16 Rue Emile Lavandier
L-1924 Luxembourg

166, rue de Beggen
L-1220 Luxembourg

twitter.com/eurociu
fb.com/eurociu/
[@eurociu](https://twitter.com/eurociu)

www.eurociu.eu

