

Wrocław, Poland – Symposium brings the European capital of hearing implantation



On 25 to 27 April, all eyes of the [#HearingLoss](#), [#Hearing](#) & [#CochlearImplants](#) gave their attention to Wrocław, Poland where an international Symposium was organized by the Polish association of people with hearing implants "Hear without borders" and EURO-CIU (European Association of Cochlear Implant Users).

Representatives of 31 countries (over 200 people from all over the continent) participated in the XII EURO-CIU Symposium in Wrocław, including deaf people who hear through auditory implants, their families and employers, representatives of the World Health Organization, outstanding professors of medicine from Poland and Europe (from Austria, Spain, Germany, Great Britain and Italy). Participants of the Symposium discussed the meaning of hearing implants – electronic hearing prostheses of the only sense that humanity invented, thanks to which most deaf people do not learn sign language, children do not study in special schools and adults may do the dream job.

EURO-CIU supports the fight of the Association Hear Without Borders, the Polish organisation, who has been acting on behalf of patients with an auditory implant since its inception, operates on a national scale and in a consistent and long-lasting way educates the public about the treatment options for deafness and hearing loss and fights for systemic changes and real impact, among others on the issue of legislation in Poland regarding implants. The Association is struggling to provide every implanted patient regular replacement of the external part of the auditory implant (sound processor), which in Poland is 100% reimbursed by the NFZ.

Why is it so important? The use of sound processors that are older and have several years, in practice for patients in their everyday life means worse hearing quality and the inability to use the latest available technologies that significantly improve the quality of hearing. The sound processor, like any electronic device, wears out after some time of its daily use and requires regular replacement. Upgrading an older sound processor may cause difficulties in communicating with the environment, and difficulties in continuing studying or working. For children, it may limit development.

EURO-CIU is a non-governmental and non-profit association which was established in Luxembourg in 1995; consist of 32 national member associations from 24 European countries and represents more than 220,000 cochlear implant users across Europe.

To know more about it, follow [#EUROCIU19](#) Symposium or visit: [www.eurociu.eu](http://www.eurociu.eu) or our Polish member <http://slyszecbezgranic.pl/>

**Adrian Szatkowski**

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[Summary of two days scientific programme – Day 1](#)



*(Photos: Adrian Szatkowski opening the Symposium and welcoming guests from the City Hall. Video presentation from Shelly Chadha from WHO)*

**NOTE - Author of the Summary: Dr. Monika Lehnhardt-Gorjany**

The XII symposium of EURO-CIU was held on two days, the first mainly dedicated to medical topics and the second to (re)habilitation and socio-economical issues

There were over 200 delegates at the Symposium. On the first day in the Opening Ceremony led by Adrian Szatkowski, it was good to welcome representatives from the City Hall.

Following the Opening Ceremony, there was a video presentation from Dr. Shelly Chadha from the World Health Organization about "The impact of hearing loss worldwide". She also talked about various initiatives how to increase global awareness and how to prevent hearing loss.

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*(Photos of harpist, singer and keyboard player)*

During the Opening Ceremony, a professional harpist and cochlear implant users played music for us, to show the world that deafness is not a barrier for music. Thanks to their Cochlear Implants, these users can play music for everyone's enjoyment. There are no limits! We keep breaking communication barriers!

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The first Round Table "Implant programs in Europe – treatment standards for children and adults" was moderated by Dr. Sandro Burdo from Italy. Participants in the panel were Prof. Dr. Roland Laszig from Germany, Prof. Dr. Piotr Skarzynski from Poland, Prof. Dr. Witold Szyfter from Poland and Nadine Cochard from France.

We heard that things have changed dramatically over the 35 years, since cochlear implantation with multi-channel devices started in Europe in 1984. This applies to the indications (degree and kind of hearing loss), age limits, additional handicaps - all of which have broadened significantly. Improved imaging techniques (e.g. DVD), facial monitoring, the choice of a series of implant models with different electrode arrays helps the surgeon to perform cochlear implantation also in difficult cases.

The consensus was that bilateral (two CI) /binaural (CI and HA) is mandatory in case of bilateral severe hearing impairment or deafness at least in countries where we can financially afford it.

Some prefer simultaneous CI surgery (e.g. Sandro Burdo)"save the brain", some see pros and cons of simultaneous versus sequential (Roland Laszig emphasizes that the anaesthesia takes 4 hours in case of simultaneous) and all agree that the time difference between the first and the second surgery needs to be short (Nadine Cochard).

The key messages from this Round Table were that research has proven the importance of the brain plasticity in the very early years of life. We have no time; we must not lose valuable time! Carol Flexer said it and Todd Houston says it: the diagnosis of severe hearing loss or deafness is a neurological emergency situation. We have only 2,000 days, because this is the time frame when the plasticity of the brain is fine. But 2,000 days is only 5 years.

Another message we heard is equally important: get the baby ready for communication before surgery! Do not wait until the surgery. Parents must not expect the miracle to happen after surgery and first fitting.

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The presentation "The importance of hearing loss for patients, their families and the environment" by Eulalia Juan Pastor from Spain highlighted the consequences of hearing loss not only for the person affected, but for their families and their social environment.

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Roland Laszig presented on "Single Sided Deafness" and documented the leading role of the Freiburg University Clinic in this field and on "Advantages of bilateral implantation" and showed us from scientific data, collected in his clinic, that in all cases bilateral compared to unilateral or bimodal provides better results. Advantages being hearing in noise and localization of sound.

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In the second Round Table of this day “Cochlear Implants – When are they indicated and when not”, Dr. Monika Lehnhardt-Gorjany as the moderator asked 16 questions to the panel, which consisted of Dr. Sandro Burdo from Italy, Nadine Cochard from France, Prof. Dr. Roland Laszig from Germany, Eulalia Juan Pastor from Spain, Maria Rotkiel from Poland, Dr. Józef Mierzwiński from Poland, Prof. Dr. Piotr Skarzynski from Poland, Prof. Dr. Witold Szyfter from Poland.

Some of the main conclusions were again, that indication has changed dramatically over the decades. In the “early days” according to FDA a child had to be 4 years of age to be considered as a candidate, now we “wonder”, whether the optimum age is nine, seven or five months.

We also understand that 35 years ago nobody would have considered providing a cochlear implant to a 91-year-old lady. Now we do, as we understand the benefit is fantastic not only for children but also for elderly people. Deafness for them is linked with social isolation, greater mental & physical problems and dementia. We have lots of studies from brain research, it is available, and it is accessible. For those interested, we could provide relevant links.

A very important recommendation from Roland Laszig is: do not replace a functioning implant, just because you believe that with a modern model implant combined with a more modern speech coding strategy in a later sound processor version the results will be better. This is not necessarily the case. He cautioned us: when a person has many years of experience with a given speech coding strategy and this will be changed, it may be very difficult for him / her and it may take a long time to get benefit from the change. We need to bear in mind that many of our CI recipients have a job and under these circumstances it may cause a serious problem at least short-term. The message here again is: we hear with the brain!

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The panel discussion with patients and representatives of the patients’ families under the title “Expectations of patients”, moderated by Dr. Katarzyna Bienkowska, was very enjoyable. It confirmed the diversity we are encountering. It is not only the diversity of expectations – obviously as everybody is different – but we also still see huge differences in the health care services provided for hearing loss in all countries, even in Europe. We would hope that this situation will change in the not too distant future.

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**Photo: Dr. Monika Lehnhardt-Gorjany**

The last two presentations of the day were on "Neonatal Hearing Screening". Prof. Dr. Witold Szyfter showed us the results after 15 years in Poland and Dr. Monika Lehnhardt-Gorjany gave an overview on the situation in Europe. In Summary: not all is perfect, but we can see progress everywhere.

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#### [Summary of two days scientific programme – Day 2](#)



**(Photo: Sue Archbold)**

**NOTE - Author of the Summary: Dr. Monika Lehnhardt-Gorjany**

Dr. Sue Archbold from the UK started the second day with an excellent lecture on "Rehabilitation has more than one name – different rehabilitation needs of children and adult cochlear implant users". She emphasized the necessity for training teachers in mainstream schools. It is mainstream schools where our children with CI are mostly now and where their needs should be met.

The other impressive message she conveyed to us is the change in where (re)habilitation should happen. CI recipients and parents of children want to become independent. They want to see a shift in location, from the clinic to the home environment, where counselling and coaching is happening. Sue suggested that we may not want to call it (re)habilitation any longer. They want to be empowered to be

able to manage the technology themselves, with specialist support. With the availability of modern communication means – like Skype, Online Rooms, Apps etc. – and with the connectivity provided by modern implants, this is possible.

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Eulalia Juan Pastor followed with her lecture on "The role of sound processor fitting in rehabilitation" and it was a perfect fit with the previous presentation. She showed us a fantastic visualization of the increasingly complex technology, with more and more products appearing on the market in a puzzle. And this highlighted again the need for training of the recipients. She also emphasized that "Data-logging" is not to be perceived as "Big Brother is watching you", but as a great tool to learn and that what children need is not "(re)habilitation", but parenting, coaching, education and fun!

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Dr. Zdzisława Orłowska-Popek talked about speech perception and speech production under the title "Proprietary methods of rehabilitation" and then the fun element was again highlighted in Dr. Katarzyna Bienkowska's presentation on "Modern methods of therapy of people with hearing implants". She made it clear that (re)habilitation has to go far away from the clinical settings and from the face to face therapy between therapist and child. She also emphasized the idea of empowering parents, training parents and encourage them to use all the skills they have, but sometimes lose when they get the diagnosis that their child is deaf. She showed examples of different emotions and situations parents can perceive as opportunities to communicate effectively with their child.

Two commercial presentations from Cochlear and MED-EL followed.

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Julie Ligeti from Cochlear on “Addressing the challenge of unmet need for hearing technology across all age groups – what role can producers play” told us, that only 3% of adults who need a CI do get one. A really very small percentage. So, there is an urgent need for advocacy and awareness initiatives.

During her talk, Julie also reminded us of how Malala Yousafzai inspires young people with cochlear implants. The World Hearing Day video “Be Everything You Can Be” is well worth watching, so [click on this link](#).

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Eva Kohl talked about the important topic of music for CI users. She described very well what CI recipients feel with music and we all remember one quotation: “Music is yoga for my ears”.

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*(Photo: Tricia Kemp, Trustee of The Ear Foundation; Julie Ligeti, Cochlear; Sue Archbold - launching the document)*

Sue Archbold launched a Briefing Paper that she and Brian Lamb had written for The Ear Foundation, bringing together the growing evidence on the associations between hearing care, cognitive decline and healthy ageing in an accessible format. It suggests that ensuring hearing health will support healthy ageing and early access to hearing aids and cochlear implants are recommended.

The document can be downloaded from The Ear Foundation's website by [clicking here](#), and then going to the pdf link towards the bottom of the page.

*With thanks to Cochlear for supporting this work; it is the work of the authors. Huge thanks to a number of reviewers who informed our understanding. Brian Lamb and Sue Archbold, for The Ear Foundation*

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A very enjoyable panel discussion, again moderated by Dr. Katarzyna Bienkowska "Users of implants in the labour market" let us believe that there is a very good relationship between employers and their "bodies", and they seem to be proud of each other. The message to take home was: "Everybody can really do what he/she wants" and this is more than encouraging.

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**(Photo: Parents of children with cochlear implants)**

Finally patients from Poland and from Belgium shared their stories with us: "Stories of patients as a carrier of information about the problem of hearing loss" and we learnt a lot about what is happening in Belgium with very different kinds of support that is available especially also in schools in this country.

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... and many thanks to Dr. Monika Lehnhardt-Gorjany - not only for providing a verbal summary on both days, but for providing a brief review of the Symposium for this special edition of our Newsletter,

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[Extraordinary General Assembly 2019](#)



Our President, Teresa Amat, opened Day 3; and first of all, an Extraordinary General Assembly was held to bring the Statutes and Internal Rules up to date. After debating each point, the voting was unanimous.

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[General Assembly 2019 - Summary](#)



*(Photo: members attending the General Assembly)*

M<sup>a</sup> Teresa Amat, Coordinator of AICE Federation, has been re-elected as President of EURO-CIU (the European Cochlear Implant Users Association), in the first round with absolute majority of votes, re-validating her presidency that will continue to be maintained by Federación AICE (Spain).

The Vice President elections were close, but the winner was Cochlear Implant User Robert Mandara from Kuulolitto (Finland). The elections took place within the Annual General Assembly of EURO-CIU that was held on Saturday, April 27 in Wroclaw (Poland). EURO-CIU brings together 32 cochlear implant associations from 24 countries across Europe.

The new Executive Committee is made up of M<sup>a</sup> Teresa Amat (Spain) President; Robert Mandara (Finland) Vice President; Ervin Bonecz (Hungary) Vice President; Beatriz Cusmai (Italy) Secretary; Henri-François Baiverlin (Belgium) Treasurer; Leo de Raeve (Belgium) Scientific Advisory Board Member; Fernando Giménez (Spain) Consultant Member for the website; and Brian Archbold (United Kingdom) Advisory Member for the Newsletter, as well as Sari Hirvonen-Skarbö (Finland) as EDF (European Disability Forum) delegate.

In her speech accepting the position, M<sup>a</sup> Teresa was excited and grateful for the trust again granted: "Four years are not enough to revolutionize Europe and give visibility to hearing loss" and she has appreciated having four more years to continue the fight. Robert Mandala, the new Vice President wants to raise awareness of cochlear implant users such as himself.

The new team on the Board wants to motivate young people to be involved in the associative work. Among the next objectives, the Board will lead projects that reach all countries and strengthen EURO-CIU as an interest group in the European Parliament, in addition to continuing to fight for accessibility to communication and the rights of cochlear implant users and people with hearing loss, with the solidity and transparency that the new times demand.

EURO-CIU celebrates its 24th anniversary this year and, with its 6 elections held, M<sup>a</sup> Teresa becomes its fourth president and the first woman to have held this position, revalidating it. From the AICE Federation, we wish you luck and that your executive committee, under your new mandate, will be even more successful than the previous one and that we will see many advances and achievements for the benefit of all cochlear implant users in Europe.



***(Photo: On all three evenings, Dinners were arranged in local restaurants, giving us all an opportunity to renew friendships)***

During the day, the activities from the previous General Assembly were presented. The Annual Report would be forwarded to members, and it would also be available on EURO-CIU's website.

Dr Leo de Raeve gave a detailed presentation on the annual survey of cochlear implant users - both adults and children. There are some big differences in our member countries.

We then turned to EURO-CIU projects. Firstly we discussed Cochlear Implant Day 2018 and actions for 2019. There was a report on the WHO meeting on 3 March, and on the new videos project "CI Voices".

Dr Sue Archbold then gave a presentation on the latest Spend2Save version 2.0 and copies were available for members in various languages. The summaries are available to download from the EURO-CIU website. [Click here.](#)

On behalf of Sarah Allen and Clare Allen, Sue brought members up to date on the European Friendship Week, concluding with a [video taken in 2018](#). For details of this year's event, [click here](#).

The next section of the meeting was relating to activities on a high European / International level. There were a wide variety of topics, including EDF, Platform - Coexist in Harmony, the European Parliament, Accessibility Act, Lobbying in the European Parliament and Commission and finally the World Hearing Forum. We are all most grateful for all the work that Teresa Amat and Laia Zamora have put into this important aspect of our work. The profile of EURO-CIU has never been higher.

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***(Photo: Left to right: Sari Hirvonen-Skarbö (Finland) as EDF (European Disability Forum) delegate; Leo de Raeve (Belgium) scientific advisory board member; Ervin Bonecz (Hungary) 2nd Vice-President; Beatrice Cusmai (Italy) Secretary; Henri-François Baiverlin (Belgium) Treasurer; M<sup>o</sup> Teresa Amat (Spain) President; Robert Mandara (Finland) 1st Vice-President; Brian Archbold (United Kingdom) advisory member of the Newsletter and Fernando Giménez (Spain) consultant member of the website.)***

Following a presentation by our Treasurer, Henri-François Baiverlin and a Statement of the Auditors, the Accounts were approved. Approval and discharge of the Board was agreed. As mentioned earlier, elections for President, Vice President and Treasurer took place. Please see photo above showing the new Board with its Advisors.

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***(Photo: another social event was to have a guided tour of Wroclaw in small groups)***

The final section of the day was to learn of projects being undertaken by our member organisations and to welcome a new member.

Germany presented their DCIG Youth Program, followed by Spain covering the important topic of bullying of cochlear implant users and their project to develop this at a European level. Georgia was then welcomed as a new member.

Next year is an important one for EURO-CIU, as we celebrate our 25th anniversary. Members are asked to consider two issues, and send their ideas to the Board:

1. The design of a special logo for our 25th Anniversary;
2. And how to raise additional finances to increase our profile on this important occasion.

The Workshop and General Assembly 2020 is to be held in Brussels and will be a joint collaboration with our two Belgian member organisations, APEDAF & VLOK-CI. As we would like to involve Members of the European Parliament in our celebrations, we must await the outcome of the forthcoming European Elections before we decide upon the date - we need to know when the Parliament is sitting in Brussels rather than Strasbourg!

Our German member organisation, DCIG, has offered to hold the Symposium and General Assembly 2021 and this is likely to be held in Munich in the week after Easter - so around 9 - 11 April 2021.

Finally, the EURO-CIU flag was passed from Poland to Belgium - with thanks to Poland for holding an outstanding event, and thanks in advance to Belgium for hosting us next year.

Our Polish friends are rightly proud of their city, so one of the evening events was for us all to have a guided tour of Wroclaw in small buses like golf buggies - it was fun and very interesting!

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