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The International Federation of Hard of Hearing People (IFHOH) is an international non-governmental organisation representing the interests of more than 466 million hard of hearing people worldwide.

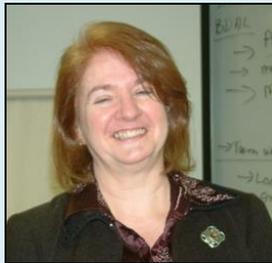
*IFHOH is registered as a charitable organisation at Vereinsregister Amtsgericht, Hamburg, Germany
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IFHOH Journal includes information about IFHOH activities, world news related to hearing loss, articles written by IFHOH members, and much more. It is published four times a year and posted on IFHOH's website, www.ifhoh.org. The Editor can be reached at journal@ifhoh.org.

All the views expressed in IFHOH Journal are those of the individual writers. and do not necessarily reflect

From the Editor's Desk

From the Editor's Desk



Carole Willans
Editor and IFHOH Special Advisor

Dear IFHOH friends,

The COVID-19 pandemic has caused disruption at all levels of society around the world. Most aspects of our personal lives have been affected, for example in the areas of employment, education, access to medical care, connections with families and friends, to name only a few. There must be very few corners of the world that have not felt at least some disruption. The pandemic has caused not only loss and grief, but also fear and division.

However, a new phrase has been coined - "the new normal" - which refers both to the present time and the future. Many people may feel helpless right now, but I invite each one of you to consider that you are not helpless because you still have the capacity to choose and the power to act. The new normal is making countries, communities and organizations think and grow politically, socially, and educationally. It is an opportunity to consider accepted and well-practiced methodologies in areas such as advocacy and awareness-raising, and to consider how these have become inappropriate or even impossible to do. For example, holding a major in-person international conference is currently not only inappropriate, it is in fact impossible. In short, the time is right for new thinking that is in keeping with "the new normal". The key to future success is to make sure that we are not just expressing a knee-jerk reaction to an immediate need, but that we are creating a new world of world community of advocacy and awareness-raising.

Over the last few months and together with many other organizations and groups, the International Federation of Hard of Hearing People has responded to its wider community in addressing some of the many difficulties we all face as a consequence of the pandemic. Joint statements have been issued, webinars on a variety of topics have been held (and more are coming) - - all of which are creating a greater sense of community, shared purpose, and collaboration among hard of hearing people around the world. For example, I have "attended" many international events (on-line) which otherwise would not have been accessible to me before. Let us all see "the new normal" as a time for opportunity and hope.

- Carole

IFHOH President's Message



Dear Friends,

The COVID-19 pandemic is still with us as are its impacts. Everyone is affected and hard of hearing persons are particularly impacted by the use of opaque masks that cover the face limiting lipreading and by requirements for social distancing which also limits communication.

Each of us have our stories. I was recently required to go to the hospital emergency department and faced the challenge of trying to communicate with various health professionals despite being clear about having a hearing loss. In one exchange, the staff member asked me "What is your first name?" three times or so I thought; it turned out that she was actually asking me "What is your date of birth?" She did not vary her statement and I did not immediately clue into the miscommunication, bearing in mind that when faced with a health emergency we may not always be at our best. (By the way, my health issue resolved itself and I am fine.)

The experiences of other hard of hearing persons were shared in a recent survey conducted by IFHOH and IFHOHYP, with our regional networks, EFHOH and APFHD. A report of the results is on our website (<https://www.ifhoh.org/>). Several of the responses stood out for me including:

My doctor has put me out on stress leave due to my job being stressful already with using walkie talkies; now to add on to that stress customers [are] wearing masks and getting upset with me due to not hearing them, and the plex glass has now muffled out sound. I will probably not be going back to my job.

Dr.'s appointment is via phone - not the same as in person. Telephone conversation is difficult to understand. Words are blotted out or misinterpreted.

Our advocacy work related to the pandemic continues with the International Disability Alliance (IDA) which is planning a cross-disability survey in November; further details will be posted on our website when available. We continue to emphasize the need for clear masks or face shields, captioning access, use of speech-to-text apps for one-on-one conversations, use of technology for minimizing the impact of social distancing, and the need for positive attitudes to meeting our access and communication needs.

Unfortunately, the continuing pandemic means that a new date has not been scheduled yet for the postponed Congress from the previously scheduled 27 and 28 May 2020 in Budapest. We will keep you posted on developments.

Other organizations have also had their events altered or changed because of the pandemic. The International Disability Alliance, which consists of regional and international disability organizations, including IFHOH, had to postpone its annual meeting. At a September on-line board meeting, the board extended the terms of office of existing executive committee members to 30 June 2021. Thus, I will continue as First Vice-President; Ana Lucia Arellano as President, Yannis Vardakastanis as Treasurer, and Klaus Lachwitz as Secretary. Continuing second and third vice-presidents are Fred Schroeder and Vanessa dos Santos.



Members of the IDA Executive Committee shown in pre-pandemic days (left to right) IDA Treasurer Yannis Vardakastanis, Ruth Warick, IDA Executive Director Vladimir Cuk, and Ana Lucia Arellano

IDA provides support for the work of IFHOH including securing funding for us to undertake education and COVID-19 projects. Their assistance in setting up webinars using their zoom platform is also much appreciated.

In August, we held our first webinar on COVID-19 impacts of hard of hearing persons. On 15 October we held another webinar on *Cochlear Implants: Increasing Awareness and Advocacy*. During the session, results were shared of a landmark International Consensus Paper outlining minimum standards of care for adults with severe to profound hearing loss. Also discussed was the IFHOH cochlear implant policy paper and plans to update it. Our thanks to Cochlear Limited and MED-EL for providing seed money to make our CI project possible, with full editorial control remaining in the hands of IFHOH. We are also involved in discussions with professional and consumer colleagues regarding advocacy CI initiatives; both Avi Blau, Vice-President of IFHOH, and I participated in an on-line meeting in early September.



Shown representing IFHOH at an online meeting about cochlear implants are Ruth Warick and Avi Blau

Hearing Care for ALL is the theme of World Hearing Day, taking place 3 March 2021. At that time, the much-anticipated World Report on Hearing will be released. More information is included in this Journal and on the [WHO webpage](#).

As part of the activities related to raising the profile of hearing loss issues, I am Co-Chair of a Committee of the WHO's World Hearing Forum which is collecting stories of Changemakers. Changemakers are individuals and organizations who are making a difference for improving hearing health care awareness, and access. Most of you are already Changemakers in your own way; now is the opportunity to share your hearing health care story and increase awareness worldwide about hearing loss.



Ruth Warick with WHO officer Shelly Chadha taken in pre-pandemic days

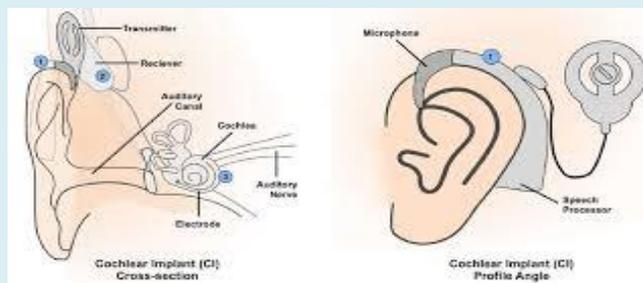
We have exciting times ahead of us; thank you for all that you do and will continue to do to increase awareness and advocacy for persons with a hearing loss.

All the best,
 Ruth Warick
 IFHOH President
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Cochlear Implants: Raising Awareness and Access

Cochlear implants have been around for 40 years and have greatly improved the lives of recipients. Yet, despite advances in the technology and its benefits, there is a lack of awareness about cochlear implants and too few adults with hearing loss, who could benefit from the devices, have access to cochlear implants. A landmark International Consensus Paper published in *JAMA Otolaryngology* on 27 August 2020 outlines minimum standards of care for adults with severe to profound hearing loss. An online webinar session about the paper generally, and more specifically about advocacy efforts and the role of consumers, took place on 15 October 2020.



International advocacy leaders and speakers for the session were:

- **Dr. Harald Seidler**, MD, past DSB President, International Federation of Hard of Hearing People (IFHOH) representative on the Consumer and Professional Advocacy Committee and co-chair of the Committee
- **Mrs. Barbara Kelley**, Executive Director, Hearing Loss Association of America and co-chair of the Consumer and Professional Advocacy Committee
- **Ms. Darja Pajk**, Representative of the European Federation of Hard of Hearing People on the Consumer and Professional Advocacy Committee
- **Mr. Bowen Tang**, President of the International Federation of Hard of Hearing Young People
- **Dr. Ruth Warick**, President of the International Federation of Hard of Hearing People

The session was moderated by Mr. Avi Blau, Vice-President of IFHOH. Special thanks to the International Disability Alliance for its support of this webcast, and to Cochlear Limited and MED-EL for their support for the IFHOH CI Advocacy Project.



23rd Session of UN CRPD Committee



The UN CRPD Committee held its 23rd session from 17 August to 4 September 2020. Due to the COVID-19 pandemic, it was held online and did not include reviews of States' parties to the *Convention on the Rights of Persons with Disabilities*.

During this session, the Committee:

- Adopted views on seven individual communications under the Optional Protocol to the CRPD; as well as a follow-up report on views on previous individual communications;
- Took note of contributions by organisations of persons with disabilities and national human rights institutions highlighting violations of the human rights of persons with disabilities, in particular of those residing in institutions, in the context of the COVID-19 pandemic;
- Advanced in its collaborative work for the informal joint working group on the impact of COVID-19 on the work of Treaty Bodies;
- Advanced in its collaborative work with the Committee on the Rights of the Child and the Committee on the Elimination of all Forms of Discrimination against Women;
- Established a working group on the deinstitutionalization of persons with disabilities;
- Advanced its work to develop a general comment on Article 27 of the CRPD (work and employment);
- Provided information on the *International Principles and Guidelines on Access to Justice for Persons with Disabilities*, adopted jointly by the Special Rapporteur on the Rights of Persons with Disabilities, the Committee on the Rights of Persons with Disabilities and Special Envoy of the Secretary-General on Disability and Accessibility.

The Committee's 24th session is scheduled for 8 to 26 March 2021, subject to confirmation. The countries to be reviewed are Bangladesh, Djibouti, Estonia, France, Jamaica and Venezuela. The 15th Pre-Sessional Working Group will take place, subject to confirmation, 29 March to 1 April 2021. The countries involved will be identified later.

Source : <https://www.internationaldisabilityalliance.org/23rd-crpd-session-closes>

UN Appoints New Special Rapporteur



Professor Gerard Quinn is the new UN Special Rapporteur on the rights of persons with disabilities

Professor Gerard Quinn has been appointed as the new UN Special Rapporteur on the rights of persons with disabilities. Given his extensive experience and expertise, IFHOH and the worldwide disability community look forward to the implementation of this important mandate in the coming years. The Special Rapporteur's contribution will be essential to the successful implementation of the United Nations Disability Inclusion Strategy as part of ongoing efforts to ensure that the United Nations system is responsive in relation to disability inclusion.

Among his priorities, Prof. Quinn said that he will work to ensure that the voices of persons with disabilities are heard, in global responses to general calamities caused by Covid-19, climate change and the scourge of armed conflicts. He highlighted the need for systemic change to underpin the gains of the UN CRPD, and to focus attention on the cultural and structural changes needed for the Sustainable Development Goals to be attained.

Prof. Quinn is a Professor Emeritus in law at the National University of Ireland, with a long career in public service. He sits on the scientific committee of the European Union Fundamental Rights Agency (EU FRA, Vienna), and has led the delegation of Rehabilitation International during the drafting of the UN CRPD. To learn more about Mr. Quinn, [follow this link](#).

World Hearing Day 2021

The countdown to [World Hearing Day 2021](#) officially began 12 September 2020!

3 March 2021 will mark the launch of the World Report on Hearing and is an opportunity to raise awareness on this topic among policymakers and the general public.

The theme of the World Hearing Day is:

**"Hearing Care for ALL
Screen. Rehabilitate. Communicate"**

The World Hearing Day 2021 and the *World Report on Hearing* present a global call for action to address hearing loss and ear diseases across the life course.

The key messages of World Hearing Day 2021 target:

Policy makers

- The number of people living with unaddressed hearing loss and ear diseases is unacceptable.
- Timely action is needed to prevent and address hearing loss across the life course.
- Investing in cost effective interventions will benefit people with hearing loss and bring financial gains to the society.
- **Governments must act to integrate person-centered ear and hearing care within national health plans for universal health coverage.**

General public

- Good hearing and communication are important at all stages of life
- Hearing loss (and related ear diseases) can be avoided through preventative actions such as: protection against loud sounds; good ear care practices and immunization.
- Hearing loss (and related ear diseases) can be addressed when it is identified in a timely manner and appropriate care sought
 - People at risk of hearing loss should check their hearing regularly
 - People having hearing loss (or related ear diseases) should seek care from a health care provider



The announcement depicts the key graphics around which the 2021 World Hearing Day campaign will be based. It is available in the six UN official languages (Arabic, Chinese, English, French, Spanish and Russian). Thanks to the support of members of the World Hearing Forum, it is also available in Bengali, Georgian, German, Hindi, Italian, Indonesian, Javanese, Korean, Portuguese, Swahili, Turkish, Urdu, and Vietnamese.

Edit-able formats are available upon request. The purpose of doing so is to make it easy for partners to adapt these visuals to suit their own campaigns. If you would like to receive the edit-able formats of the announcement, kindly use the [following form](#).

More information on the campaign will be available on the [WHO webpage](#). Other advocacy materials including flyers, banners will be made launched during the webinars: **A glimpse into the World Report on Hearing and the World Hearing Day 2021**, on 3-4 November 2020.

All partners and countries are invited to join this initiative by organizing events. A toolkit for planning for World Hearing Day and dissemination of the World Report on Hearing will be available during the webinars in November and registration opened soon after.

We hope that the World Hearing Day 2021 will be a massive **call to action**. All sectors can demonstrate their leadership by making this year's event the largest one the country has ever seen and use this opportunity to motivate action.

Kind regards,

WHO ear and Hearing care team

#[safelistening](#) #[worldhearingday](#) #[WorldHearingForum](#) #hearingcare



World Health Organization News



On 22 and 24 September 2020, the World Health Organization (WHO) presented a webinar: [Task sharing for EHC \(ear and hearing care\) in times of COVID and beyond - World Report on Hearing webinar series](#). Several IFHOH members participated in this online event.

The purpose of the webinar was to share:

- Share information on the concept of task sharing for ear and hearing care (EHC), as reflected in the *World Report on Hearing*,
- Share experiences from countries on EHC provision through task sharing, and
- Outline steps to maintain and strengthen EHC services during the pandemic and beyond.

Dr Bente Mikkelsen (WHO) introduced the topic. Dr Kaloyan Kamenov (WHO) provided facts and figures explaining the need for task sharing. For example, 56% of African countries have less than one ear, nose throat (ENT) specialist per million inhabitants, as compared to European countries where there are more than 50 ENT specialists per million inhabitants. Task sharing is a way to deal with the shortage of professional human resources by allowing doctors and specialists to be freed up and having other health care workers and/or community workers giving appropriate health care, such as hearing testing, basic ear health care, raising awareness of hearing health in the community, etc. During the 22 September webinar, Dr Suneela Garg, and Dr Wakisa Mulwafu spoke of their experiences in the field in the context of India and Malawi respectively. Dr Shelly Chadha (WHO) acted as moderator and made a presentation on the recommendations of the *World Report on Hearing* with respect to task sharing. Finally, there was an opportunity for questions and answers.



Dr Bente Mikkelsen and Dr Shelly Chadha, both of WHO

The same webinar was held twice to be accessible to all time zones (22 September and 24 September) under the leadership of the WHO Ear and Hearing Care team. Please see the next article for more information on what task sharing is all about.

Task Sharing for Ear and Hearing Care

By Carole Willans, IFHOH Special Advisor

I attended the World Health Organization (WHO) webinar described in the previous article. The information and innovative ideas presented seemed so useful and important that I thought it important to share more of its substance for the benefit of IFHOH members who were not able to participate. (Source: WHO PowerPoints presented during webinar.)

Understanding task sharing begins with understanding why it is needed. Nearly 450 million people around the world require care to address issues linked to their hearing loss. Access to ear and hearing care (EHC) is inequitably distributed and, in many countries, there is already a serious lack of human resources. To make matters worse, the WHO estimates that by 2050, the number of people with hearing loss is likely to nearly double.

WHO Workload Indicators of Staffing Need (WHO WISN) is a human resource management tool to measure health workers' workload. It was applied in a wide variety of scenarios, including for example ear examination and cerumen cleaning in Oman, hearing testing in Zambia, and post hearing aid fitting and counselling in Russia. The results indicate gaps between existing and required professional cadres. In Zambia, for example, 620 audiologists would be needed to do hearing testing within an area where only one audiologist exists. With this kind of shortage in cadres comes an immense workload for the professionals that are on hand. However, if certain tasks are shared with other health workers, up to 54% of the current load of EHC professionals would be reduced.

To help understand what task sharing can look like, let us consider some examples of implementation.

In Zambia, there are currently 12,000 nurses. These nurses are being successfully trained through a two-week course to be able to properly give hearing tests in addition to their other daily tasks. Once all these nurses have completed training and started carrying out hearing tests, the workload of Zambian audiologists would be reduced by 48%.

In Russia, there are 100 audiometrists, 445 speech therapists and 1 000 sign language interpreters who can potentially be trained and share counselling tasks with audiologists to reduce the latter's workload by almost 54%.

In the republic of Kiribati (formerly the Gilbert and Ellice Islands), a community-based nurse-led EHC service for children provides a cost-effective way to implement preventative measures against serious medical complications from ear disease in children using the school setting. Two nurses were trained on common conditions and treatment, on use of the otoscope and the voroscope, etc. They also received visits from Ear Nose and throat (ENT) teams from Australia and Taiwan, which helped to build their competency and clinical capacity. Training was then extended to include audiometry and middle ear function testing. The result of all these efforts is a dramatic decrease in chronic ear problems of students.

As another example, task sharing is a key strategy in the implementation of the National Programme for Prevention and Control of Deafness in India, where there are limited professional human resources for 78 million people with disabling hearing loss. Health workers have been trained to serve as multi-purpose workers for EHC; they raise awareness of good EHC practices, identify hearing loss, manage common ear problems, and refer cases to a tertiary centre. They can even be trained to do infant hearing screening during their home visits. Community level workers have been trained to raise awareness of good EHC practices, identify hearing loss in children at an early age, and provide care for pregnant women. General practitioner doctors can carry out school check-ups, cerumen removal, diagnosis and management of ear diseases. Most interestingly, ophthalmic assistants have been trained as EHC assistants. In India, there already exists a network of vision centres where ophthalmic assistants work. These centres have been further developed so that they have become an integrated model of eye and ear care at the primary level. Training based on WHO primary EHC manuals was done and basic equipment for EHC was provided to the vision centres. The presenter explained that task sharing has reduced the number of hospital visits thus leaving time for overburdened health systems to deal with the pandemic.

In Malawi, what is called "task-shifting" has been a process of delegating some tasks to less specialized health workers. A trial was carried out to assess the feasibility of training community health workers to provide primary-level EHC, including identification of patients with ear and hearing disorders, referral of patients to services, and treatment of simple ear conditions. The key findings were that the training was proved feasible and acceptable, and that the community health workers were able to identify patients and refer them as appropriate.

In conclusion, task-sharing is among the key WHO recommendations to ensure universal access to quality people-centred EHC and will be profiled in the *World Report on Hearing* to be published 3 March 2021.

World Data Forum

By Carole Willans, IFHOH Special Advisor



The virtual World Data Forum took place 19-21 October 2020. Pre-recorded sessions were available for viewing starting 12 October, and live sessions (presentations followed by a period for questions and answers) took place over the official 3-day period.

There were a broad range of issues and innovative solutions addressed throughout this lengthy event - too many to list. Just to give one example of a recurring theme, frequent reference was made to uncovering opportunities for countries to help each other leverage administrative data to facilitate and inform national responses to the Millennium SDGs. The idea is that official governmental statistics are generally of high quality and reliability and there are several ways to unearth data gems that can be useful to the public.

More directly relevant to IFHOH and its members were discussions on the ways and best practices for communicating not only official statistics, but for communicating these in a manner to is useful to the public. Even more important is the necessity of communicating useful information to the public in an accessible manner. Examples of useful information that should be based on solid statistics and communicated to the public in an accessible manner is information on COVID-19, where it is occurring around the world, what are the various treatments that are being used, the rate of hospitalisation versus home treatment, patients' nutrition, and so on.

During the World Data Forum, the Stakeholder Group of Persons with Disabilities, the International Disability Alliance, World Blind Union, and CBM Global Disability Inclusion organised a session on persons with disabilities and COVID-19 data collection and disaggregation efforts, which was held 21 October. During this live session, the role of disability data advocacy in response to the COVID-19 pandemic was discussed. It was explained that this necessarily includes the exchange of information, the sharing of good practices, and understanding the ways that the communities of persons with disabilities can collaborate on disability data collection, disaggregation, and analysis in the context of COVID-19. In addition, it was emphasized that it is important to identify and implement ways to strengthen the engagement of persons with disabilities and their representative organizations so that they can effectively influence COVID-19-related evidence-based policy changes to ensure no one is left behind. The importance of addressing the needs of hard of hearing persons in terms of communication accessibility, and the specific ways to do so, was referenced during the panel, and I had the opportunity to reinforce this issue during the period for questions and answers.



EFHOH News



By Marcel Bobeldijk, EFHOH President

EFHOH and its Board of Directors continue to work at many levels despite the current pandemic. Projects currently include the Live Text Access (LTA) project. I have already described this

project to *EFHOH Journal* readers. Basically, it is a strategic collaboration between educational and non-educational partners that aims to tackle the need for harmonized training in the field of real-time intralingual subtitling. To find out more about this project and/or to keep posted on developments, I invite you to visit the website: www.ltaproject.eu. The DAAD

Euroletter recently published an interesting article in German about the LTA project; here is the link: <https://www.daad.de/kataloge/epaper-daadeuroletter69/#34>.



EFHOH is also involved in the Tinnitus Assessment Causes Treatment project (TIN-ACT). The members of this consortium held a virtual workshop on 21 to 24 September 2020 consisting of expert presentations and discussions on scientific contributions, as well as insights into the industry behind hearing devices. More information can be found on the website: www.tinact.eu.

The EFHOH AGM 2021 will be held in the first part of 2021. Later this year we will inform you about the details.

I also want to mention that the European Association of Cochlear Implant Users (EURO-CIU) held its 25th General Assembly on 3 October 2020; here is the link to the most recent edition of its newsletter: <https://www.efhoh.org/euro-ciu-newsletter-september-2020/>.

Please note that EFHOH has had two information pages on Facebook. There are a page and a group. EFHOH has decided to concentrate on just one channel for information and discussion, so as of 1 October 2020 the EFHOH page will be closed, and you are all invited to join and actively participate in the EFHOH Facebook group. The group is named EFHOH and here is a direct link: <https://www.facebook.com/groups/28392292467>. You can also follow us on Twitter: @efhoh



European Disability Forum

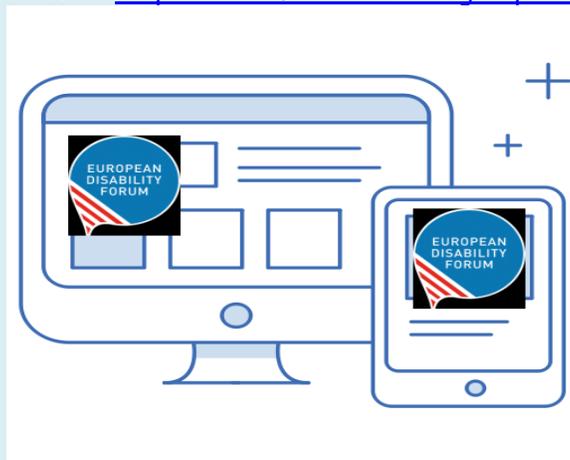
What happened at the EDF during the summer?

As always, the EDF team has been working on accessibility, focusing on several areas of interest, including the following:

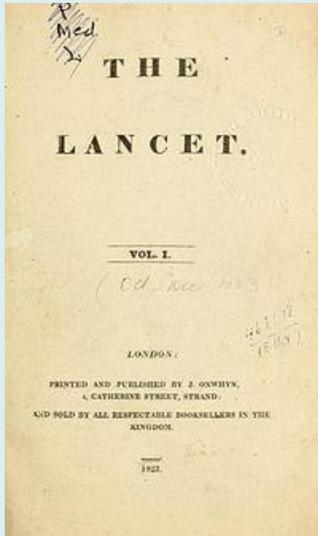
- Transposition of relevant accessibility legislation:
 - *European Accessibility Act*: EDF published an analysis, held a webinar and the toolkit for transposition. A second webinar - this time focusing on transposition will soon be available on its website
 - *Audiovisual Media Services Directive*: EDF published a toolkit and a webinar.
 - *European Electronic Communication Code*: EDF published a toolkit and a webinar on this topic as well
- Implementation of adopted accessibility legislation:
 - EDF is following how EU governments apply the *Web Accessibility Directive* to see if they are effectively ensuring that all public sector websites are accessible to persons with disabilities.

In addition, the EDF has an upcoming webinar about the draft European Standard (EN 17210) on the accessibility of the built environment, which it hopes will be adopted soon. In the meantime, it continues to work on the harmonised *European Standard on Accessible Technologies* (EN 301 549).

To keep up to date on EDF activities, you can visit its website at www.edf-feph.org or follow the EDF on Facebook at: <https://www.facebook.com/groups/28392292467/?fref=ts>.



Lancet Commission on Hearing Loss



The Lancet is an independent weekly peer-reviewed general medical journal. Founded in 1823, it is among the world's oldest and best-known general medical journals. It publishes original research articles, review articles ("seminars" and "reviews"), editorials, book reviews, correspondence, as well as news features and case reports. The journal has editorial offices in London, New York, and Beijing.

The Lancet has commissions to focus discussions on key health issues, such as the Lancet Commission on Hearing Loss (LCHL) following a *Lancet* review in 2019 on the state of global hearing health care and possibilities for improvement. The purpose of the LCHL is to identify ways to reduce the global burden of hearing loss. A report from the LCHL is expected to be published in 2022.

On 30 September 2020, the LCHL hosted a panel of speakers from all over the world to speak about the needs and populations of people with hearing loss and how the LCHL can have a positive impact. IFHOH arranged for Jessica Niemela to be one of the speakers on the panel, and she presented the perspective of a young person living with hearing loss. With her kind permission, we share with you the content of her presentation.



Lancet Commission on Hearing Loss: The Perspective of Young Hearing Impaired People

By Jessica Niemela

Contrary to the way we often understand it, the burden of hearing loss is not carried exclusively by older adults. I am here to share with you today that hearing loss is in fact a condition that shapes the lives of our young people across the globe. In March 2020, the World Health Organization has reported that out of 466 million people worldwide with hearing loss, 34 million of these people are children. I would like to briefly state the need and evidence-based impact of 1) early identification and treatment of hearing loss; 2) support systems in place for deaf/hard of hearing youth in the school settings; and 3) social and community development amongst deaf/hard of hearing youth.

Early identification of hearing loss and appropriate treatment before 6 months of age are the very first steps in order to provide access to either listening and spoken language and/or sign language for a child. Furthermore, when a child is identified with a hearing loss and treated in a timely manner, the outcomes for literacy rates and psychosocial development are optimal.



Newborn hearing screening programs started in the 1990's and are now considered a standard program in many developed countries. There are, however, still developed countries that do not have national standards for delivering early hearing screening programs, and the situation in developing countries is even more complicated. In Canada, for example, according to the Canadian Infant Task Force, early hearing programs are insufficient in seven provinces and territories. There is a growing body of research that demonstrates that efficient newborn hearing screening programs are not only critically beneficial to the child and their families with hearing loss, they are also very cost-effective to the economy. The argument is simple: If a child has access to developing language then they have a better chance to be a productive member of society as a result of better language skills and quality of life.

When children with hearing loss go to mainstreamed schools, research shows that they benefit greatly from remote microphone systems in the classroom, support from a hearing resource teacher, and other services such as live captioning or a sign language interpreter.



When normal hearing children are learning they need the signal to be significantly louder than the room's noise level in order to learn effectively, compared to adults. Children with hearing loss need that signal to be even louder to get the same outcomes as their normal hearing peers and hence the need for remote microphone systems. The hearing resource teacher, also known as the

teacher for the deaf and hard of hearing, plays a pivotal role for the student with hearing loss where they are available. They not only support the student's use of classroom equipment, but they are a mentor who teaches the hard of hearing student fundamental self-advocacy skills that are essential to their academic success and adult life. For students who have a greater degree of hearing loss or use sign language, their access to learning can be further increased with use of live captioning and/or a sign language interpreter.

As humans we are social beings, and we thrive when we feel like we belong. All over the world we are starting to see the growth of hard of hearing communities, which is similar to their Deaf community counterparts. There are national and international organizations such

as the Canadian Hard of Hearing Association, the Hearing loss Association of America, and the International Federation of Hard of Hearing Young People, whose share the common mission: to bring hard of hearing individuals together. Social and community development for children with hearing loss can come in the form of schools, activities, and events where they can interact with their hard of hearing peers. Children, therefore, do not have to experience hearing loss in isolation, and through these programs, they can learn how to advocate for themselves, develop good communication strategies, gain friendships, increase self-esteem, establish self-identity, and foster a sense of belonging.

As a person who grew up living with hearing loss and now in my career as a pediatric audiologist, I have the privilege of experiencing and guiding families through their own child's journey through hearing loss. I have witnessed the poor outcomes of a child who has been identified later in life, with no additional support at school and no hard of hearing community to turn to. On the flip side, I have witnessed the positive outcomes of a child who has been identified early, who is well connected to her hearing resource teacher, and has a strong sense of identity partly due to her hard of hearing community involvement. It is critical that we advocate for the hearing health of our future generations to come. When we set up our youth for success it is better for the individual, society, and for the economy.

References

Canadian Infant Task Force (2019). 2019 report card on Canadian early hearing detection and intervention programs. *Speech-Language & Audiology Canada, Canadian Academy of Audiology.*

Hintermair, M. (2000). Hearing impairment, social networks, and coping: The need for families with hearing-impaired children to relate to other parents and to hearing-impaired adults. *American Annals of the Deaf, 41-53.*

Israelite, N., Ower, J., Goldstein, G. (2002). Hard-of-hearing adolescents and identity construction: Influences of school experiences, peers, and teachers. *Journal of Deaf Studies and Deaf Education, 7(2), 134-148.*

The Joint Committee on Infant Hearing (2019). Year 2019 position statement: Principles and guidelines for early hearing detection and intervention programs. *The Journal of Early Hearing Detection and Intervention Programs, 4(2), 1-44.*

World Health Organization (2017). Global costs of unaddressed hearing loss and cost-effectiveness of interventions: a WHO report.

World Health Organization (2020). Deafness and hearing loss. <https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss>

Zanin, J., & Rance, G. (2016). Functional hearing in the classroom: assistive listening devices for students with hearing impairment in a mainstream school setting. *International Journal of Audiology, 55(12), 723-729.*

Asia Pacific Federation of the Hard of Hearing and Deafened



This report on the current activities of the Asia Pacific Federation of the Hard of Hearing and Deafened (APFHD) is focused on projects being carried out in Cambodia and in Vietnam. The other country members do not have much to report in terms of activities due to obstacles posed by the nature of their work in the context of having to meet social distancing requirements caused by the COVID-19 pandemic.

CAMBODIA

HOPE Cambodia carries out its monthly activity of ENT screening and treatment. This also includes providing free hearing aids for patients who have hearing loss.



VIETNAM

The Center for Research and Education of the Deaf and Hard of Hearing (CED) has been able to carry out some activities for the Hard of Hearing community such as:

- Granting 48 new and used hearing aids for children and adults with hearing loss (15 males and 12 females) who live in 17 cities and provinces in Vietnam (data reported for 8 months of year 2020); and

- In collaboration with the Vietnamese American Scholarship Fund (VASF) and the Center for the Encouragement of Self-Reliance (CESR), granting 12 scholarships for 12 students with hearing loss who live in the difficult circumstances and study at CED. The scholarship value is of 65 USD per month and applies to the school year 2020 - 2021.

Vietnamese Project - Promoting the Initial Legal Support and Implementation of Regulations on Medical Examination and Treatment for People with Hearing Loss

By Duong Phuong Hanh - Founder and Executive Director of Center for Research and Education of the Deaf and Hard of Hearing (CED)



Duong Phuong Hanh working with Vietnamese children, and adults, with hearing loss

The Center for Research and Education of the Deaf and Hard of Hearing (CED) is implementing step by step a project approved by the Justice Initiatives Facilitation Fund (JIFF) "Promoting the Initial Legal Support and Implementation of Regulations on Medical Examination and Treatment for People with Hearing Loss (deaf, hard of hearing and deafened)".

This project aims to support people with hearing loss in Ho Chi Minh city to access public medical services in the contexts of patient visiting and of medical examinations, as well as to support some hospitals to meet the *Hospital Quality Criteria*, version 2.0 (issued together with Decision No. 6858/QD-BYT, November 18, 2016 by the Minister of Health, Vietnam).

This project will be implemented over a one-year period, and it will include the following activities:

1. **Communication:** Coordinating with lawyer/legal support center to provide awareness and information relating to Vietnam's *Hospital Quality Criteria*; providing information, legal policy, rights and benefits for people with hearing loss based on relevant legislation concerning people with disabilities, on the International

Convention on the Rights of Persons with Disabilities, on legislation regarding children, on legislation regarding the elderly, and on the law in matters of social insurance.

2. **Training:** Skills for supporting people with hearing loss in hospitals, designed for health care staff and for public health students.
3. **Training:** Sign language interpretation.
4. **Research:** Assessing capability of hospitals in meeting the needs of patients with hearing loss; case study relevant to Vietnam's *Hospital Quality Criteria*.
5. **Publishing a handbook:** on skills for supporting people with hearing loss in the context of patient visitation or of medical examination.

The project starts in September 2020 and ends in August 2021.

IFHOHYP News

By Bowen Tang, IFHOHYP President



The International Federation of Hard of Hearing Young People (IFHOHYP) has posted its first ever Board vlog on its recently updated website at www.ifhohyp.org. Three Board members appear in the vlog: Leonie van Berlin, Kave Noori and Bowen Tang. The purpose of the vlog is to provide information on the latest developments within IFHOHYP over the past year and to describe how young hard of hearing people can get involved and make a difference. IFHOH Journal readers are invited to get the latest news about IFHOHYP and its activities on the website.



The new IFHOHYP vlog

Calendar of Events

Calendar of Events

11th IFHOH World Congress – Postponed!

IFHOH World Congress 2020 was to be held in Budapest, Hungary, 27 to 29 May 2020. IFHOH and EFHOH had planned to hold their BGM/AGMs during the Congress. IFHOHYP had scheduled a study meeting. Due to the COVID-19 pandemic, the Organizing Committee has postponed the Congress to ensure the safety of all participants.

While the new date for the Congress is yet to be set, we would like to inform you of our intention that the program remain intact with the same sponsors, and the registrations of delegates will be automatically transferred. We are working on details to set a new date. Please check our website regularly for updates: <https://www.ifhoh2020budapest.com/>

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30 October 2020: Online Conference on COVID-19 and Disability

The European Disability Forum and Lebenshilfe invite you to an online conference on *COVID 19 and Disability - Building a Better Future* taking place on Friday, 30 October 2020 (four hours in length). It is open to all and will explore the impact of COVID 19 on persons with disabilities in Europe. It will also help in drawing up recommendations for policy makers at National and European levels. The conference will be in German and English. There will be live captioning in German and English, and International Sign language interpretation. The programme will soon be available here: [Conference on COVID 19 and Disability- building a better future](#). Please register through this link: https://zoom.us/webinar/register/WN_rLWVy0GqQleMDTOZ5rXMvw.

* * * * *

EDUCATIONAL CONFERENCE & TRADE SHOW

JUNE 3-5 2021 CHHA SASKATCHEWAN
Delta Bessborough Hotel, 601 Spadina Crescent East, Saskatoon, Saskatchewan

Canadian Hard of Hearing Association
Association des malentendants canadiens **CHHA.ca**

Information: <https://www.chha.ca/2021-conference-and-trade-show/>

**13 - 17 September 2021 - International Conference for Pastoral Care
among Hard of Hearing - IVSS Churchear**



Location: Haus Hainstein in Eisenach, Germany

Information: <http://www.churcheear.org>

Contact: Barbara Adamus, board member

Email: post@churcheear.org

The International Conference for Pastoral Care among Hard of Hearing was postponed this year and is now scheduled to take place September 13 to 17, 2021. The conference site remains the same.

First part of 2022 - Women Deliver 2022 Conference

Location: TBD

Information: at WD2022.org

Contact: Cara Bronander

Email: cbronander@womendeliver.org

Every three years, the Women Deliver Conference galvanizes momentum for gender equality. It is a bold and diverse gathering, a fueling station of ideas, and generator of action, convening thousands to identify solutions and drive change for girls and women. WD2022 will take place in the first half of 2022. The location and dates will be announced by the end of 2020. Organizers say that, regardless of location, WD2022 will have a robust digital program and global dialogue component - making participation open to everyone. Organizers have been conducting a global community survey and based on this guidance, specific themes, tracks, and sessions will be developed. IFHOH representatives are among the persons consulted so it can be expected that the events will be accessible to hard of hearing people. Find out more at <https://www.wd2022.org/>.



IFHOH JOURNAL – EDITOR’S NOTE

Let us help you attract participants to your events!

Please send me an email providing me with details.

Carole Willans, Editor, *IFHOH Journal*, email: journal@ifhoh.org

News Bytes

News Bytes

SECRETS OF THE EAR'S MATURING SENSORY HAIR CELLS



Dr. Ronna Hertzano

Scientists at the University of Maryland and Stanford University recently conducted a study on the maturation process of the sensory cells that line the inner ear, known as hair cells, to better understand their role in our sense of hearing, and particularly, to know why these cells are prone to irreversible damage from stresses such as excessive noise. It is hoped that the information obtained from this study will lead to regenerative treatments for this kind of hearing loss. In fact, it appears that the study offers an important advance by demonstrating how a single protein can determine whether embryonic hair cells mature into adult hair cells or follow a different path entirely.

The lead researcher, Dr. Ronna Hertzano, reports: "Our findings explain why *GFI1* is critical to enable embryonic cells to progress into functioning adult hair cells. These data also explain the importance of *GFI1* in experimental protocols to regenerate hair cells from stem cells. These regenerative methods have the potential of being used for patients who have experienced hearing loss due to age or environmental factors like exposure to loud noise." The studies were conducted on mice are a just a small piece of a very complex puzzle.

(Source: Secrets of maturing hair cells point to new treatments for hearing loss by Nick Lavars, 15 September 2020, <https://www.newatlas.com/medical/maturing-hair-cells-treatments-hearing-loss/>.)

SENSORY FRIENDLY SOLUTIONS PODCAST



A new [podcast series](#) was recently launched by Sensory Friendly Solutions to give voice to daily life with sensory challenges. The world is noisy, bright, busy, and often overwhelming. With COVID-19, you likely find it more difficult to between home and back to school, or back to work and back to your community. Especially with the barrier of masks making it harder to communicate. There is the added stress when it starts to feel even a little crowded and you worry about getting too close to other people. Find sensory-friendly solutions in everyday life on our new podcast. Enjoy a 10-part deep dive into the world of your senses, sensory sensitivity, and [sensory overload](#).

STUDY SHOWS GREATER PREVALENCE OF HEARING LOSS AMONG PEOPLE IN LOWER SOCIOECONOMIC POSITIONS

Those in lower socioeconomic positions are up to twice as likely to have hearing loss than those in higher socioeconomic positions, a British study has found. The study examined whether socioeconomic and modifiable lifestyle factors are associated with hearing loss among older adults in the U.K.

The study found that variation in education, occupation, income and wealth, which are important determinants of health inequality, are associated with hearing loss. In the study, socioeconomic position was strongly associated with the likelihood of hearing loss in older adults, with those with higher levels of education, income and wealth being less likely to be associated with hearing loss, while manual occupations increased the likelihood of hearing loss. Read more:

<https://www.hear-it.org/more-hearing-loss-among-people-lower-socioeconomic-positions>

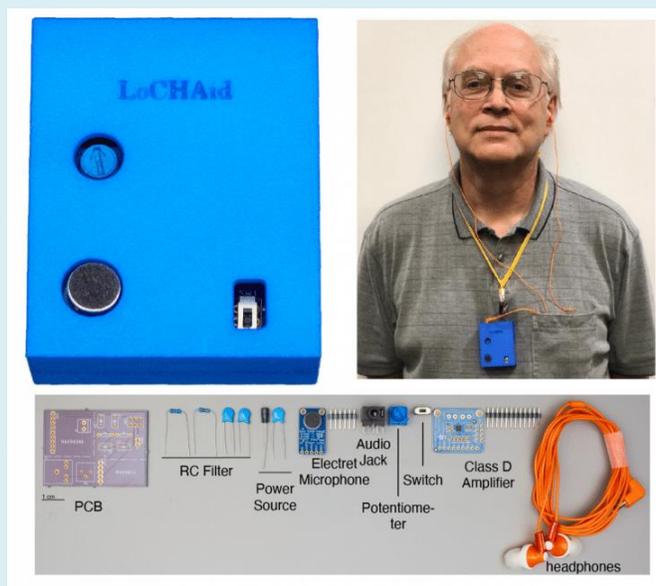
ADHEAR COVID-19 SYSTEM AT MED-EL



To support patients, candidates and centers during COVID-19, the MED-EL Corporation is using ADHEAR, a non-surgical system. The company says that this has sped up its journey toward remote support to help provide uninterrupted service to recipients and the professionals working with its products. [READ MORE](#) (Source: *Audiology Online*)

ULTRA-LOW COST HEARING DEVICE

LoCHAid is a very low cost proof-of-concept device designed by researchers at the Georgia Institute of Technology (U.S.A.). Its inventors say that it can be built with "a dollar's worth of open-source parts and a 3D-printed case." (The electronic components cost less than a dollar if purchased in bulk, and that does not include assembly or distribution costs.) It is designed to be easily manufactured and repaired in locations where conventional hearing aids are priced beyond the reach of most people. "The minimalist device is expected to meet the World Health Organization's targets for hearing aids aimed at mild to moderate age-related hearing loss. The prototypes built so far look like wearable music players instead of traditional behind-the-ear aids."



[READ MORE](#) (Source: *Hearing Health & Technology Matters*)

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This issue features Bernafon!



Since 1946, Bernafon has been passionate about developing quality hearing systems that enable people with hearing difficulties to enjoy authentic listening experiences. With Swiss Engineering, precision technology, and our commitment to individual service, we strive to exceed our customers' expectations. Our aim is to provide extra value to our partners every day. Bernafon representatives and employees in over 70 countries fulfill our vision to help people with impaired hearing communicate again without limitations.

IFHOH JOURNAL

The deadline for submissions for the next issue is November 15, 2020.
Contributions are welcome!

The preferred length for articles is one page (400 to 500 words). Short and long articles, from 25 to 1,500 words, may also be accepted. News bytes and announcements of coming events are appreciated, including photographs and illustrations. Please send pictures in jpeg format and files as rich text or word documents. Many thanks!

Carole Willans, Editor, *IFHOH Journal*, email: journal@ifhoh.org



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The International Federation of Hard of Hearing People (IFHOH) is an international non-governmental organisation representing the interests of more than 300 million hard of hearing people worldwide. IFHOH is registered as a charitable organisation at Vereinsregister Amtsgericht Hamburg, Germany (Nr. 69 VR 10 527) and is also an International Non-Governmental Organisation having special consultative status with the United Nations' Economic and Social Council (ECOSOC). IFHOH is a member of the International Disability Alliance (IDA) and works closely with the UN system using the Convention on the Rights of Persons with Disabilities as a tool for change.



IFHOH Board

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IFHOH Board (from left to right): Heikki Niemi, Avi Blau, Ruth Warick, Patrick Gift Egessa, Marcel Bobeldijk and Hanh Duong Phuong (Hanh is photo-shopped in)