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In This Issue

From the Editor's Desk - by Carole Willans	3
IFHOH President's Message – by Dr. Ruth P. Warick	4
IFHOH BGM Postponed to 2021	7
Joint Statement on Accessible Face to Face Communication during COVID-19	8
COVID-19's Impact on Hard of Hearing Persons	10
IFHOH Fellowship Opportunity	12
World Health Organization News	13
EFHOH News – by Marcel Bobeldijk	14
European Disability Forum	16
Cochlear Implant Treatment for Adult Hearing Loss: Landmark Paper Published	17
United Nations: Empowerment of Women and Girls – by Carole Willans	18
Asian Pacific Federation of the Hard of Hearing and Deafened	20
Situation of Hard of Hearing and Deafened People during Pandemic and Disaster in Nepal – by Neeta Keshary Bhattarai	22
Welcome to New IFHOH Member – Uganda Federation of the Hard of Hearing	24
IFHOHYP News (incl. COVID-19 The Ultimate Game of Trust) – by Bowen Tang	25
FEPEDA Launches Family Survey – by Sari Paloposki	28
US Task Force on Hearing Aid Compatibility – by Juliëtte Sterkens	29
Calendar of Events	30
News Bytes	32
IFHOH Sponsor – Amplifon	34
IFHOH Mission	35
IFHOH Board of Directors	36

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 - Nr. 69 VR 10 527.

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, <u>www.ifhoh.org</u>. The Editor can be reached at <u>journal@ifhoh.org</u>.

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

Dear IFHOH friends,

We live in interesting times. While each of our countries may be experiencing the COVID-19 pandemic in different ways, there are so many commonalities that in a sense it can feel like a uniquely global experience. People have been reaching out to each other despite physical separation. This includes reaching out over international borders, even though many of these borders are closed. Technology has helped many of us to reach out and touch (virtually!) many family members and friends, sometimes even people we have not communicated for many years. More of us are looking on-line for important human connections. And it seems to me that despite restrictions to movement, most of us have been busier than ever.

IFHOH has much of the same experiences. As you know, it has had to postpone its World Congress and Biennial General Meeting. The usual in-person meetings with other international groups are not taking place. But this does not mean that IFHOH and its representatives are any less busy in their efforts to make the world a better place for hard of hearing persons. Now more than ever, IFHOH is working at achieving a delicate balance between public good and the rights and dignity of individuals.

This issue of *IFHOH Journal* contains information on IFHOH activities during the pandemic. First and foremost, there is a focus on ensuring that measures taken to deal with the pandemic do not have an unjustified adverse impact on people who are hard of hearing. Dealing with masks is an example of this kind of problem. In addition, in this issue you will learn of many instances where IFHOH and its members are already working to ensure that people who are hard of hearing hold their rightful place in the "new normal" of the post-pandemic world.

Together, we are finding hope.

- Carole

IFHOH President's Message



Dr. Ruth P. Warick, IFHOH President

Dear Friends,

The last few months have been among the busiest ever, contrary to some assumptions that the COVID-19 pandemic has ushered in a period of low activity. Our advocacy work has increased due to the pandemic itself, and due to the necessity to reschedule plans and to conduct more activities through on-line interactions.

IFHOH was faced with having to contend with postponing its Congress scheduled for May 27-29, 2020 in Budapest. Due to the continuing impact of the COVID-19 pandemic, a new date has not yet been scheduled but we will let you know as soon as it is finalized. We also had to consider how to deal with our biennial general meeting which was scheduled to be held during the Congress on May 27, 2020. We are registered in Germany and consulted with German authorities with the help of Juergen Schaeding. As a result, we postponed the 2020 BGM, including the election of officers, to next year, and we conducted an e-mail vote for approval of documents that the German tax authorities required to be filed this year. The documents included our *financial reports, audited statements and activity report for 2018 and 2019.* My thanks to the IFHOH membership for unanimously approving these documents.

Our work related to the pandemic has involved advocacy for promoting access to information and promoting masks that are not face-covering given widespread requirements for the use of face masks. In March, we wrote to the WHO Secretary-General to request captioning for their news briefings; the request was granted.

In July, we conducted a survey about the COVID-19 impact on our members, jointly with the International Federation of Hard of Hearing Young People (IFHOHYP), with the involvement of our regional networks, the European Federation of Hard of Hearing People

(EFHOH) and the Asia-Pacific Federation of the Hard of Hearing and Deafened (APFHD). The survey is posted on our website (<u>https://www.ifhoh.org/</u>) and our first webinar was held August 24; a second one was scheduled for August 31 due to a zoom outage affecting the first webinar.

We have also been active in the cross-disability movement campaigns related to COVID-19. We have worked to ensure our key issues and messages are reflected in more general messages of the International Disability Alliance (IDA) and the International Disability Development Consortium. On May 25, I was a speaker at one of their webinars to make sure that issues affecting hard of hearing persons are addressed.

We plan to hold more webinars this autumn. One relates to cochlear implants. We are reviewing and revising our Cochlear Implant Policy Statement and increasing our advocacy efforts as far too many adults who can benefit from cochlear implants do not have them. Another webinar will be about the education issues in developing countries, centred



around a report to be released next month about Inclusive Education: Realities Facing Hard of Hearing Learners in Nepal and Uganda. An announcement will be posted on our website about the dates for these webinars when available.

IDA has also produced a report about Inclusive Education, and I was involved in the task team for the report and other inclusive education activities including webinars. The report is on the IDA website at <u>https://www.internationaldisabilityalliance.org/news-inclusive-education-2020</u>.



Ruth Warick speaking during an IDA webinar

We continue to be active with the World Health Organization which has had to postpone the release of its World Report on Disability. We have contributed to this report and look forward to its release on the new planned date of March 3, 2021; this date coincides with World Hearing Day. To ensure sufficient amplification of the messages from the report, we have been actively involved with professionals and other colleagues to develop strategies to increase awareness of hearing loss and of the importance of hearing care.

On the membership front, we are pleased to welcome the Uganda Federation of the Hard of Hearing to the IFHOH family as a general member.

So, to conclude, COVID-19 might have caused the postponement of live events and derailed travel and in-person meetings, but it has not stopped our work. We are resilient and we are continuing to work. I do look forward to the day when the restrictions are fully eased but, until then, we will carry on with working in front or behind the scenes for hard of hearing issues and our movement.

Stay safe and well, Ruth Warick IFHOH President

IFHOH - International Federation of Hard of Hearing people <u>info@ifhoh.org</u> <u>www.ifhoh.org</u> <u>www.facebook.com/groups/IFHOH</u> <u>www.twitter.com/IFHOH</u>



Ruth Warick ensuring IFHOH representaton at many key online events – a new way of working!



IFHOH BGM Postponed to 2021

Due to the coronavirus pandemic, the IFHOH International Congress in Budapest scheduled for May 27-29, 2020 has been postponed, along with the IFHOH Biennial General Meeting (BGM) of May 27.

As there is still much uncertainty about international travel and the holding of large inperson events, no new date has yet been established. IFHOH members will be advised of the new scheduled date for the Congress and BGM as soon as it is determined.

The terms of office of the current board members have been extended until elections in 2021. This way of proceeding is in accordance with new legal guidelines in the *German Civil Code* (Document 19/18111 passed by the German Parliament on March 24, 2020). IFHOH is registered in Germany and has consulted extensively with German authorities. We are grateful to the current board members who have all agreed to continue to serve IFHOH and its members.

IFHOH has filed its audited financial statements, its financial report, and an activity report for 2018-2019 with the German tax office. General members of IFHOH voted on the documents by e-mail. In accordance with IFHOH's constitution, only general members were eligible to vote, if their fees were paid up. This way of proceeding by e-mail voting is unprecedented because of these unusual times. We thank our members for their cooperation in approving these documents by email.

Everyone at IFHOH is looking forward to a Biennial Meeting in 2021 in Budapest!

If you have comments or questions, please email them to us at info@ifhoh.org.

Please keep well and safe. Best regards,

Ruth Warick, President, IFHOH and Hanh Duong Phuong, General Secretary, IFHOH Info@ifhoh.org



Joint Statement by IFHOH, IFHOHYP, WFD and WFDYS

August 31 2020 - Statement on Accessible Communication for Deaf and Hard of Hearing People during COVID-19 Pandemic <u>Click here for International Sign version</u>

The COVID-19 pandemic has brought about important public health officials from many countries making unprecedented decisions which have had significant impacts on people's lives. The International Federation of Hard of Hearing People (IFHOH), the International Federation of Hard of Hearing Young People (IFHOHYP), the World Federation of the Deaf (WFD) and its youth section, the World Federation of the Deaf Youth Section (WFDYS) and welcome measures taken to ensure public safety. Facial coverings and social distancing are two common protection strategies that pose potential barriers for deaf and hard of hearing people.

In addition to linguistic input, deaf and hard of hearing people rely heavily on facial expressions, speechreading and other visual input to support our understanding of conversation partners. Most hard of hearing persons communicate by oral means whereas most deaf persons communicate using national sign languages; however, visual cues from the person communicating are important for both groups. Face-covering masks and not using visual means of communication alongside linguistic input greatly impedes communication. Cooperation between all parties in a conversation is necessary in order to ensure accessible communication for everyone.

Hard of hearing persons define accessibility as a practice that will ensure equal access for all hard of hearing persons in all forms of communication. Accessibility may be technological (e.g. assistive listening devices, hearing loops, speech-to-text services, or apps) or nontechnological (e.g. pen and paper, clear view of speaker's face to allow speechreading). We believe that the current means of personal protections can be adapted to create an accessible environment which allows for clear communication with hard of hearing persons.

Full accessibility for deaf people is reached when all aurally transmitted information and communications are provided in national sign languages. The use of the national sign languages will ease the implementation of safe distancing measures as its use does not require any physical proximity. In addition to making public information available in national sign languages, information should be communicated via visual means as outlined throughout this statement.

We request government officials, private businesses, non-governmental organizations, cultural, educational, public and social service institutions consider the following recommendations in their responses to COVID-19:

• Mandate the use of clear, transparent face masks and shields for all workers who communicate frequently with the public (a working document on the Global Inventory of Clear & Transparent Face Masks/Shields can be found on the link<u>here</u>). A stock of

transparent masks should be available in every hospital to be used when deaf and hard of hearing people come in, and deaf people must be given access to national sign language interpreters upon request in advance of a visit. Alternatively, some hard of hearing persons may require access to a captionist.

- Provide essential information in text format in public spaces, particularly in medical settings (e.g., a list of frequently asked questions at the reception). To ensure maximum access for all, this information should be supplemented with visual aids. It is also recommended that printed information contain a QR code to access this information in national sign languages, or via the provision of remote sign languages interpretation services.
- Use speech-to-text apps to facilitate communication for one-to-one conversations. Reduce background noise (e.g., music) at restaurants and shops so deaf and hard of hearing people can more accurately use automated speech apps to follow one-to-oneconversation.
- Adopt a positive attitude towards communicating with deaf and hard of hearing people with visual language practices. These include using national sign languages, gesture-based communication, writing with pen and paper, using speech-to-text apps, and making sure the face is clear and visible.

It is worth noting that other members of our communities can benefit from these recommendations, such as those who are seniors, those with auditory processing challenges, those who communicate in different languages, and those who have other sensory needs. The use of clear face masks benefits everyone, as does providing visual information, because doing so reduces the overall potential for misunderstandings.

Accessibility is an integral part of the efforts that must be made to combat the COVID-19 pandemic. Our organisations issue this joint statement for everyone to continue to promote accessible communication through the recommendations outlined above. Clear communication and clear language use require creativity and good will from everyone. Let us navigate these challenging times together!

Dr. Joseph J Murray President of the World Federation of the Deaf

Mark Berry President of the World Federation of the Deaf Youth Section

Dr. Ruth Warick President of the International Federation of Hard of Hearing People president@ifhoh.org

Bowen Tang President of the International Federation of Hard of Hearing Young People

COVID-19's Impact on Hard of Hearing Persons

The world as we know it changed dramatically for everyone across the globe due to the COVID-19 pandemic. The impacts continue as the second wave of the pandemic is being felt. Its impact of persons who are hard of hearing has been compounded by measures such as social distancing and the wearing of masks. As hard of hearing persons we usually need to be in close proximity and to be able to read lips to augment our hearing. To assess the impact, the International Federation of Hard of Hearing People (IFHOH), with its regional networks, the European Federation of Hard of Hearing People and the Asia Pacific Federation of the Deafened and Hard of Hearing, and the International Hard of Hearing Young People (IFHOHYP) conducted a survey.

We are pleased to share the results with you on the IFHOH website (<u>www.ifhoh.org</u>) and the IFHOHYP website (<u>www.ifhohyp.org</u>) in a report entitled: *Global Report of COVID-*19's Impact on Hard of Hearing People. This report is a summary of the results in the five key areas of the survey: public accessibility, face masks and social distancing challenges, online communication, health care, and socioeconomic impact. It also provides a demographic profile of survey participants.

The report notes that the survey emphasizes that the use of face masks in medical settings, the workplace and other venues are creating communication difficulties for hard of hearing persons. There appears to be a significant lack of awareness about the existence of clear face masks or the option to use face shields in conjunction with masks. If health care workers and the general public are being urged to wear face masks, from an accessibility point of view, the use of clear masks is encouraged so that hard of hearing persons are able to read the other persons' lips and understand them.



The survey also notes that captioning features are not as visible as sign language interpretation in terms of accommodations provided. Efforts must be made to promote the use of captioning, either through a live captioner or automatic subtitling apps to access information.

Finally, hard of hearing persons face socio-economic challenges with many having lost their jobs and struggling financially. Other respondents reported experiencing loneliness and isolation.

The report concludes with 10 recommendations. READ THE FULL REPORT HERE.

On August 24, 2020, IFHOH and IFHOHYP held a webinar to further share results and discuss issues arising from the survey. It was also an opportunity to share resources and technologies that may help. Realtime captioning and International Sign Language was provided to make the event accessible. The 90 registrants represented over 20 countries, covering all five major continents; however due to technical difficulties, just over 30 registrants were actually able to participate. A second webinar was scheduled for August 31 for those who missed the August 24 event, some in part due to an internet Zoom outage.

The webinar presenters were:

Dr. Ruth Warick, President, IFHOH Mr. Avi Blau, Vice-President, IFHOH Mr. Bowen Tang, President, IFHOHYP



Special thanks to the **International Disability Alliance** for its support in the arrangements for the webcast. The International Disability Alliance and the <u>International Disability and</u> <u>Development Consortium</u> have launched an accessibility campaign to call for public health information and communications around COVID19 to be fully accessible. Read more about this campaign at: <u>https://www.internationaldisabilityalliance.org/accessibility-campaign</u>.





Position: IFHOH Fellowship Opportunity

This IFHOH Fellowship Opportunity is part of the IDA's Fellowship Programme and is funded by DFID UK under the Inclusive Futures consortium programme. The IDA Fellowship Programme has a dual objective of providing support to IDA members' operational capacity to advance the rights of persons with disabilities and to build the capacities of individual disability activists as contributors to the disability rights movement. IDA fellowships provide a unique combination of opportunities for learning, mentorship, exposure to different policy, advocacy and monitoring processes, and contribution to initiatives aimed at advancing the rights of persons with disabilities in the Global South. Fellowships are mutually beneficial for the fellow and the hosting organisation.

This particular Fellowship should support the achievement of case studies on employment issues for hard of hearing persons, conduct data reviews and key informant interviews, and prepare webinars on employment and social protection issues.

Location: Fellow must be based in Kenya, Nigeria, Uganda, or Bangladesh Gross Monthly Salary: Subject to location and experience Length of position: 9 months from October 2020 to June 2021

Fellowships should support the achievement of case studies on employment issues for hard of hearing persons, conduct data reviews and key informant interviews as well as prepare webinars on employment and social protection issues.

Criteria for Fellowship Applicants:

- Fellow must be based in either Kenya, Nigeria, Uganda or Bangladesh
- Fellow must be a hard of hearing person at least 21 years of age
- Fellow must have demonstrated interest in disability rights and involvement with the disability rights movement and, in particular, involvement with hard of hearing issues/persons
- Good communication skills in English

If interested in the position, please email <u>info@ifhoh.org</u> for the formal application package. Applications are due by September 14, 2020.

World Health Organization News



In March 2020, the WHO declared the outbreak of COVID-19 to be a pandemic. Shortly afterwards, it published a document outlining *Disability Considerations during the COVID-19 Outbreak*. This document includes an inventory of recommended actions for different stakeholders. Here are a few examples of the actions it recommends:

Actions for governments: Ensure public health information and communication is accessible – Include captioning and, where possible, sign language for all live and recorded events and communications. (...) Work with disability organizations, including advocacy bodies and disability service providers to disseminate public health information. (...) – Financial measures (commonly within a broader-based economic stimulus package) that include people with disability, such as lump sum payments for qualifying individuals, tax relief, subsidization of items and/or leniency and allowable deferral of common expenses. (...) Consider short-term financial support for disability services to ensure they remain financially sustainable if they experience a downturn in their operations. (...) – Prioritize disability caregiver agencies for access to no-cost personal protective equipment, including masks, aprons, gloves, and hand sanitizers. (...)

Actions for health-care workers: Ensure COVID-19 health care is Accessible, Affordable and Inclusive – Follow the WHO guidance to health workers during the COVID-19 outbreak. – Work to ensure all clinics providing testing and services related to COVID-19 are completely accessible. Address physical barriers; attitudinal barriers (such as social stigma against disability and the denial of essential services); and financial barriers (such as high costs related to treatment or accessing the facility). Ensure that information about the accessibility of COVID-19 health services is disseminated to people with disability and their caregivers. (...)

Actions for disability service providers: Develop and implement service continuity plans (...) - Hold additional trainings and if possible, develop online modules to prepare a new workforce and those who will take on expanded roles. - Work with other local disability and caregiver agencies to undertake the prioritization of the most critically needed disability services and those that are essential to be kept open. Identify the clients most vulnerable to a reduction in services. (...)

Actions for the community

Basic protection measures to be adopted by the general public – Follow the guidance prepared by WHO on basic protection measures against COVID-19. Take the risk of COVID-19 seriously; even if you, yourself, may not be at high risk of serious symptoms, you may pass the virus on to someone that is.

READ THE FULL DOCUMENT HERE.

Link to receive messages from the WHO Health Alert on WhatsApp.



European Federation of Hard of Hearing People





By Marcel Bobeldijk, EFHOH President

EFHOH and its member organizations continue to work hard to support the rights of hard of hearing persons during the COVID-19 pandemic. To this end, we have been working closely with IFHOH and with the

European Disability Forum (EDF) to name only a couple of examples. In collaboration with the EDF, we have been urging EU leaders to make their COVID-19 response more inclusive of hard of hearing people in terms of physical access to health services, employment supports, economic recovery and much more. We see these difficult times as an opportunity to lay the groundwork for a more inclusive Europe in the years to come.

I am pleased to announce that EFHOH has recently published an updated version of Getting the Numbers Right on Hearing Loss, Hearing Care and Hearing Aid Use in Europe, which is a joint report by the AEA (European Association of Hearing Aid Professionals), EHIMA (European Hearing Instrument Manufacturers Association), and EFHOH. It is the result of a close collaboration including Mark Laureyns, Nikolai Bisgaard, Stefan Zimmer and myself.

The report recognizes that many hard of hearing people are reluctant to seek professional help, often because they do not realize that they have a hearing problem. However, persons who have a disabling hearing loss do tend to self-identify. The joint report also recommends that age, tinnitus, occupational noise exposure, hypertension and depression be included into the evaluation of hearing loss in clinical practice.

Using EuroTrak, which is a survey based on a representative sample of the population in each of eleven European countries (Belgium, Denmark, Germany, France, Italy, Norway, Poland, Spain, Switzerland, The Netherlands and UK), 158,180 people were interviewed, including 14,306 people with self-reported hearing loss. Information from EFHOH, AEA and EHIMA also informed the best estimates on the number of hearing aids sold and used in Europe.

Interestingly, when comparing the EuroTrak results on self-reported hearing loss with the EuroStat data on the population 65 years or older we observe a very strong correlation. The higher the percentage of the population that is 65 years of age and older, the higher the percentage of the population that experiences hearing difficulties. Another interesting observation is that once the hearing loss is recognized (i.e., people report hearing difficulties) 75% consult a medical professional (mostly their general practitioner or ENT specialist). Of these, the medical professionals refer 70% to a hearing care professional. Finally, 73% of the people with a referral start using hearing aids.

The joint report explodes some myths! For example, it is generally claimed that people wait 7 years before getting their first hearing aid. The survey indicates that the average wait time is 2 years. It also often said that 20% of hearing aids are not worn and left to stagnate in a drawer. The real number is more likely around 6%. Another myth is that most people are not satisfied with their hearing aid, while in fact 77% of persons surveyed reported being satisfied with their hearing aid's performance.

You will find the link to the full report below.

<u>2020 Edition | Getting Our Numbers Right –</u> <u>European Federation of Hard of Hearing People - EFHOH</u> (https://www.efhoh.org/2020-edition-getting-our-numbers-right/)

Getting the numbers right on Hearing Loss, Hearing Care and Hearing Aid Use in Europe A Europe Wide Strategy Joint AEA, EFHOH, EHIMA Report. The June 2020 edition is now available.

www.efhoh.org

On another note, EFHOH has worked to support the European Disability Forum (EDF) in its work on the 2016 EU Web Accessibility Directive. Please read more about it in the next article in this issue under the banner "European Disability Forum".

Thanks to all the EFHOH Board members for their support!



L. to R.: Morten Buan, Vice-President (Norway), Aïda Regel Poulsen, General Secretary (Denmark), Darja Pajk, Treasurer (Slovenia), and Alf Lindberg, Board member (Sweden)

European Disability Forum

23 September: Online discussion on the Web Accessibility Directive

By September 23, 2020, all public sector body websites governed in the context of the European Union (EU) must be accessible for persons with disabilities as required by the 2016 EU Web Accessibility Directive, a milestone legislation for accessibility and digital participation in the EU.

The European Disability Forum (EDF) has co-organized an online discussion with the European Commission unit responsible for this EU law during which achievements and remaining challenges for the full implementation of the Web Accessibility Directive will be discussed. You can find more information on page 25 of this issue.

Please register through this link: <u>https://attendee.gotowebinar.com/register/8130383120502176781</u>

Join the discussion with the EDF and other disability activists, accessibility experts, representatives from the European Commission, national governments and public sector bodies who are working together to identify best practices and shortcomings of implementation.

In the meantime, why not check out...

EUROPEAN

DISABILITY

- Our <u>Web Accessibility Directive transposition toolkit (pdf)</u>
- Our page on <u>web accessibility resources</u>
- A <u>free introduction course to web accessibility</u>



The EDF's 2020 Human Rights Report is out! <u>Issue 4: Poverty and Social Exclusion - 2020</u> (doc) | <u>Issue 4: Poverty and Social Exclusion - 2020</u> (pdf)

For more on the EDF: <u>www.edf-feph.org</u> To contact the EDF: <u>info@edf-feph.org</u>

Cochlear Implant Treatment for Adult Hearing Loss: Landmark Paper Published

The world's first <u>International Consensus Paper on Adult Cochlear Implantation (</u>ICP) discussing treatment for adults living with severe to profound bilateral sensorineural hearing loss was published August 27, 2020, in *JAMA Otolaryngology*.² The paper was authored by 31 hearing experts on cochlear implant treatment.

The work of the authors was assisted by a <u>Consumer and Professional Advocacy</u> <u>Committee (CAPAC)</u> of international cochlear implant user and professional advocacy organizations to ensure the voice of users and those who might benefit from cochlear. Dr. Harald Seidler, representing the International Federation of Hard of Hearing People (IFHOH), and Barbara Kelley, Executive Director of Hearing Loss Association of America, were co-chairs of CAPAC.

IFHOH will be holding a webinar about *Cochlear Implants and the Delphi Consensus Process.* An announcement will be posted on <u>www.ifhoh.org</u> by September 20.

The Consensus Paper provides minimum standards for the provision and treatment of a unilateral cochlear implant, and covers seven categories:

- 1. Level of awareness of cochlear implants
- 2. Best practice clinical pathway for diagnosis
- 3. Best practice guidelines for surgery
- 4. Clinical effectiveness of cochlear implants
- 5. Factors associated with post-implantation outcomes
- 6. The relationship between hearing loss and depression, cognition and dementia
- 7. Cost implications of cochlear implants

The paper is an authoritative call to government policymakers, funding bodies and health professionals to understand the importance of providing accurate information, referral pathways and access to cochlear implant treatment for adults whose lives could be transformed. The Consensus Paper can also empower consumers by providing them with the right questions to ask their health care practitioners.

The full paper is available at <u>JAMA Publication</u>:

https://jamanetwork.com/journals/jamaotolaryngology/fullarticle/2769941?guestAccessKey =3dfd6ab4-bdf5-414e-b2a7-862099b04c79

United Nations: Empowerment of Women and Girls

By Carole Willans, IFHOH Special Advisor

The UN Secretary-General, Mr. António Guterres, has stated that achieving gender equality and empowering women and girls is "the unfinished business of our time", and the greatest human rights challenge in our world.

On July 21, 2020, I represented IFHOH at the United Nations' Multi-Stakeholder Hearing on Accelerating the Realization of Gender Equality and the Empowerment of All Women and Girls, a day long on-line event. This event was part of the preparations for the High-Level Meeting of the UN General Assembly on "Beijing+25". This refers to the fact that 25 years have already gone by since the adoption of the *Beijing Declaration and Platform for Action* which confirmed that women's rights are human rights and which also committed to specific actions to ensure respect for those rights.



Think about it... Women and girls represent half of the world's population and so they also represent half of its potential. Gender equality is necessary to achieve healthy economies and functional societies, which is advantageous to men and boys as well!

Therefore, it is very important to end all forms of gender violence and to establish equal access to quality education and health, economic resources, employment, and participation in political life for both women and girls.

The main theme that kept coming up during the Multi-Stakeholder Hearing was that the COVID-19 pandemic has worsened pre-existing inequalities, so it is more important than ever to push for the full implementation of the *Beijing Declaration*. Over the past 25 years there have been improvements in many different countries, but it was felt that many steps backwards were happening because of the pandemic. For example, quarantining and other necessary restrictions for health purposes have made many women and girls more vulnerable

to abuse and domestic violence, even and especially in their homes, which should be safe, but which for many, are not.



Photo credit: UN Women

Panel discussions demonstrated the levels of inequality and opportunity for women in different countries. Some of the examples given were harrowing, such as the continuation of female genital mutilation in some countries, and more generally, the exposure to violence of all kinds. Widespread inequalities arise from poverty, lack of access to education, and lack of access to adequate employment. These are all basic issues that must be addressed.

You can actually get involved with UN Women's Generation Equality campaign to mark the 25th anniversary of the Beijing Declaration and Platform for Action.



UN Women staff during Generation Equality Private Sector discussions in Kenya. (Photo: UN Women/K Okoth)

Asia Pacific Federation of the Hard of Hearing and Deafened



APFHD Vice President, Raphael D. Torralba (pictured above) reported on Facebook that he and Hard of Hearing Group Philippines members Katrina Marie Abiño and Laurence Alfrey Umali recently joined faculty members, doctors and interns in an online discussion entitled *Bioethics in Disability*. The discussion focused on disability bioethics and examined hearing disability as a model. It also aimed for medical students at St. Luke's Medical Center College of Medicine to learn from our experience regarding this and how they, in medical education, can improve their ways in conducting themselves with persons who are hard of hearing.



In addition, the Leonard Cheshire Disability Philippines Foundation and Hard of Hearing Group Philippines conducted Disability Equality Training online for the hard of hearing members in two batches. This activity is a part of the VOICE-HIVOS program. Managed by Oxfam Novib and Hivos, Voice offers grants and other forms of support for grass-root groups and organizations that have difficulty getting funding and that represent or support people living with disability or other disadvantaged groups.



"Maraming Salamat! Way Forward!"

Another online event was focused on the theme of Hand and Heart, underlining that persons with disabilities were losing their jobs because of the pandemic generally at a higher rate than other persons. Many organizations joined the fruitful discussion. APFHD Vice President Raphael Torralba said to the participants representing the different organizations: "We are inspired by your supportive and giving spirits." Participants included: Children's Joy Foundation, Inc., IBM, Best Buddies Philippines Foundation, Inc., the MMGI Group, the Federation of the Deaf-Cavite Province, Inc., DLS-CSB, DFA, HOHGP, Hard of Hearing Group Philippines, I Can Deaf Leap 3 (Miracle Warriors Foundation), Project Inclusion Network, as well as Ms. Jamie Ferrer, Ms. Rizel Espinosa. As Raphael said in closing:



Situation of Hard of Hearing and Deafened People During Pandemic and Disaster in Nepal



by Neeta Keshary Bhattarai

President of SHRUTI, a hard of hearing organization in Nepal

During the recent COVID-19 pandemic, the life of hearing loss people has worsened in Nepal. There is no access to information being provided by the state, and it is difficult for hard of hearing persons to understand conversation as all people are using facial masks and making physical distance as safety measures to deal with the coronavirus pandemic.

Life has totally changed, bringing more stress due to the increasing spread of the virus. The scenario for people with hearing loss people is worse than for others because our disability affects communication; there has been an information gap due to the lack of accessibility during this pandemic. During the other disasters as well, such as earthquake, landslide and flood, people with hearing loss have been left out, and governments have not given our issues priority to improve the accessibility needs.



Earthquake relief materials distribution by SHRUTI

Many people do not have internet access, and in rural areas network services are poor, therefore it is hard of them to connect with others. For most hard of hearing people, toll free phones are not accessible because of hearing difficulties. There is a lack of awareness of the communication needs of hard of hearing persons hospitalized due to the coronavirus, such as writing messages, using text apps, and speaking more clearly.

During the pandemic, many hard of hearing and deafened were unable to get services such as getting hearing aid batteries and having access to audiology services. Hearing aid centers were closed. Some private hearing aid centers were distributing batteries with help of their security guards in their offices. But many hard of hearing people were unable to get to the centers because transportation was halted, nor were they entitled to get a government-issued travel pass for obtaining batteries. By contrast, many other disabled people were given eligibility for a travel pass.

Schools have been closed. The Ministry of Education has formulated and imposed guidelines for alternative methods of education through television, radio and online. But all of these are not accessible for people who are hard of hearing or deafened due to more difficulty understanding speakers on-line and the lack of provision of captioning and sign language.



Family watching TV with no captioning available

Information is being provided about COVID-19 via television, radio, and telephone (ring tone). Although, sign language interpretation has been provided in the daily update about the coronavirus, but there is no live or recorded captioning services in Nepal, so hard of hearing people feel that they are forgotten members of society. We have been advocating for captioning and started to share information about providing live captioning on our Facebook Page.

We have also set up hard of hearing groups in social media and shared on the issues that they face. We also connected many hard of hearing people to hearing care services and provided psycho-social counselling as well.

Welcome to New IFHOH Member! Uganda Federation of the Hard of Hearing

The IFHOH Board has recently approved a request by the Uganda Federation of the Hard of Hearing (UFHOH) for General Membership status in IFHOH under category GM 1 with 650 members. Join us in welcoming this new IFHOH member!



UFHOH 2019 AGM

The UFHOH reports that it was founded in 2017 and is an umbrella organization for several regional groups of hard of hearing persons in Uganda. UFHOH has for the larger part of 2019 been actively involved in capacity building activities which has ensured that the organisation continues to deliver on its mandate at a national perspective. The group has gained visibility through the activities it was able to implement alone and in partnership with other disabled people organisations. A special focus is to strengthen its regional members' capacity; this is seen as a key to the achievement not only of the UFHOH's vision, but also the SDG goals as they apply to Uganda. Visit the UFHOH website at <u>www.ufhoh.com</u>.



UFHOH representatives with Ruth Warick at the United Nations

IFHOHYP News



By Bowen Tang, IFHOHYP President

IFHOHYP Website

The International Federation of Hard of Hearing Young Persons (IFHOHYP) is proud to announce that the Member and Information Committee has recently finished work on the new website for the organization. You can now find out more about us, get to know the members of our board and our committees, and discover what we do and what our past activities have been. Thanks to Karolina, Leonie, Ediz, Maria and Keegan!

Global Inventory of Clear/Transparent Face Masks

Have you seen the posts about transparent face masks for the Deaf and Hard of Hearing across social media? Sounds perfect, right? Problem solved, lip reading restored?

Our newly founded Accessibility Committee was not convinced. It does not help to see them online while you and your surroundings do not have access to them. Knowing clear face masks exist does not help you when talking to someone that wears a normal mask.



To make it easier for you to convince your friends, your workplace, or your doctors to wear one of these masks, the committee created a comprehensive resource of links and contacts to purchase them in your own country. You can access the document here -

<u>https://tinyurl.com/ycvc35r6</u>.

Great thanks go to the IFHOHYP Accessibility Committee including Raph Torralba (Philippines), Le Peng Tee (Malaysia), Sey Rubén Rodríguez (Bolivia), Irina Ivanova (Russia) and Bowen Tang

(Canada) for their effort. Do you like their work? Consider joining them by sending an email to <u>accessibility.ifhohyp@gmail.com</u>.

You still need to convince someone that lip reading is important for you and therefore you need them to wear these masks? Show them our YouTube video that highlights the importance of lip reading -> <u>https://buff.ly/2Diiedn</u>

COVID-19: The Ultimate Game of Trust *

I personally wrote an article on my experiences navigating the pandemic, originally published on the website of the Canadian Hard of Hearing Association - BC Chapter. I would like to share this story directly with IFHOH readers. (* Editor's Note: I have edited the original article for length. You can read the full article at <u>https://www.chha-bc.org/youthpsp/COVID-19-the-</u> <u>ultimate-game-of-trust/</u> published July 23, 2020.)

"Imagine, just imagine when you are no longer able to see, hear, smell, taste, or touch. Having any of these senses impeded is enough to shake anyone's confidence in navigating the world around them. For people with disabilities, this is an every-day reality which has recently become a nightmare with the arrival of COVID-19. The barriers and challenges presented by the pandemic have eroded the skills people with disabilities worked so hard to develop. In addition to being a global health crisis, COVID-19 is like the ultimate game of trust.

As a person with profound hearing loss living in Canada, I have the privilege of being able to access quality hearing care and services. Complemented using hearing assistive technology, I am able to effectively communicate in my daily interactions. There are still situations where listening is difficult (e.g., background noise) so I rely on visual cues such as reading the speaker's mouth and facial expressions. With the prevalent use of face masks, I find myself struggling to access information when visiting public places like grocery stores, medical clinics, and restaurants. While face masks keep the virus particles out, they also keep the sound in, thus distorting the speaker's speech clarity. Not only am I now faced with reduced sound quality, I can no longer use visual cues as they are completely blocked off by the face mask.

Since the start of COVID-19, these skills were thrown out the window when the cashier at the grocery store stared at me during checkout. I did not understand what she was asking, so I tried to anticipate what the question could be and gave random responses: "I am paying by credit card" or "I don't need bags". It turns out she asked if I wanted to redeem my points for the eggs I purchased. Initially I did ask her to repeat, but even then, I still could not understand, hence I started panicking and went for the alternative which ended up in me making

a fool of myself. My impulsiveness stems from not wanting to hold up the line as there were other people waiting and I also made assumptions about people's level of patience. Rather than utilizing the strategies that have proven effective before, I became frozen like a deer in the headlights, standing there at the checkout aisle, wishing this nightmare would be over.



As an advocate for people who are deaf and hard of hearing, I always strive to educate others about the impacts of hearing loss and promote the value of accessible communication. I am ashamed to admit that I did not once think of self-disclosing my hearing loss in the situation I mentioned. I need to shift my mindset: one that involves me learning to trust myself and more importantly, trust others. COVID-19 is the speeding ticket we needed to slow down and look at how we can navigate the journey to the future in a safer manner. Let us take a leap of faith in the hopes of transforming the negativity into feeling empowered. It does not take long to reap the benefits, such as during my recent visit to a pharmacy. Once I indicated that I have a hearing loss, the pharmacist was kind enough to write down what she needed from me. The interaction went smoothly, and I thanked her for her help. It is that simple.



In closing, I would like to take a page from one of my favorite childhood stories, The Tortoise and the Hare. The tortoise was underestimated for its ability to finish the race and was quickly left behind by the hare. The hare unexpectedly became the loser because of its ego and overconfidence. The common lesson we learn from the story is that slow and steady wins the race. In the context of the real world, COVID-19 is the race we are in, the tortoise represents people with disabilities who are left behind, and the hare represents

everyone else. If we do not know how to trust one another, we are all losers. If I may propose an alternative ending to the story, the hare would pick up the tortoise, the tortoise would then guide the rabbit through the path and then they would make it to the finish line together. Let us be the tortoise and the hare, let us all be the winners in life!"



Can you guess which mask Bowen prefers?

FEPEDA Launches Family Survey

By Sari Paloposki, FEPEDA President

FEPEDA is a non-governmental umbrella organization representing associations of parents and friends of Deaf and Hard of Hearing children at the European level. It is asking families across Europe to complete an electronic survey. The answers will provide FEPEDA with:

- new information on the situation of hearing impaired children and young people throughout Europe
- the views of parents of hearing impaired children and young people
- the changes in Europe since the previous surveys in 2000 and 2013.

The survey takes about 10 to 15 minutes to complete. If you find it necessary, you can return to previous questions; please note that you will have to fill in the survey in one visit. If you have more than one hearing impaired child in your family, please fill in a separate questionnaire for each one. The deadline for returning surveys is September 30, 2020.

Here are the links to the survey, according to language: English: <u>https://forms.gle/JJWDE183zyi6Xag2A</u>

Bosnian: https://forms.gle/BUoRYAVYZWRrPTKq6 Bulgarian: https://forms.gle/B585rHTSeYNVYdi58 Czech: https://forms.gle/hP2vFTkguyy5NgBX8 Finnish: https://forms.gle/nP9p7ztKBnS4yMS36 French: https://forms.gle/nCFCWx5qddzR5Ndwv6 German: https://forms.gle/nX5LFxAzEmdf7cix9 Italian: https://forms.gle/AaSXUGni9JHaJeDm9 Lithuanian: https://forms.gle/WmARf4Dq4GCdsVHr5 Russian: https://forms.gle/QRH8aK9fhjy1KQAN8 Spanish: https://forms.gle/ft24aT99RWqFVn48 Swedish: https://forms.gle/pfgMbeeaMAbHC68d8

Any questions regarding the survey and the results should be addressed to the FEPEDA Secretariat at petra.paloposki2@gmail.com.



U.S. Taskforce on Hearing Aid Compatibility

By Juliëtte Sterkens



I was asked to provide input to the HAC (Hearing Aid Compatibility) Taskforce from CTIA about cellphone use among hearing aid and CI users. (Editor's Note: The CTIA is a trade association representing the wireless communications industry in the U.S.A. The association was established in 1984 and is headquartered in Washington, D.C.)

I have been seeking to know from IFHOH members if you connect wirelessly with your hearing aids or cochlear implant to your cell phone? How that is working for you? Is it easy to wirelessly connect hearing aids (or CIs) to a smartphone? Do any

of you use the telecoil in your hearing device on your mobile phone? Does your current mobile phone emit a strong enough magnetic signal for you? (Is your reception via the telecoil strong/loud enough?) Are you using an iPhone or Android phone?) I received many responses, for which I thank you. The meeting with the CTIA did take place in mid-August, and I am looking forward to sharing its conclusions with IFHOH members when these are released. Please feel free to continue to share your experiences with me on this ongoing topic via jsterkens@hearingloss.org.

Editor's Note: Juliëtte Sterkens, AuD recently retired from her private audiology practice in Oshkosh, Wisconsin (U.S.A.) to volunteer as the National Hearing Loop Advocate for the Hearing Loss Association of America (HLAA).

IFHOH JOURNAL – EDITOR'S NOTE

Please - we want to help you attract participants to your events!

Conferences, webinars, discussion groups and other events are now being held on-line. Make your event special by opening it up to hard of hearing persons around the world! *IFHOH Journal* readers would love to participate and bring an international flavour to your event. Specify the language of the event to reach out to the entire diaspora of persons around the world who speak your language. Please send me an email providing me with details. Carole Willans, Editor, *IFHOH Journal*, email: journal@ifhoh.org

Calendar of Events

11th IFHOH World Congress - Postponed!

WORLD WITHOUT

IFHOH World Congress 2020 was to be held in Budapest, Hungary, May 27 to 29, 2020. IFHOH and EFHOH had planned to hold their BGM/AGMs during the Congress. IFHOHYP had scheduled a town hall meeting. Due to the recent spread of the COVID-19 virus in Europe and the World, the Organizing Committee has decided to postpone the IFHOH 2020 World 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: <u>https://www.ifhoh2020budapest.com/</u>

EUROPEAN

DISABILITY FORUM

23 September 2020: Online discussion on the Web Accessibility Directive

The European Disability Forum invites you to an online discussion on the Web Accessibility Directive, co-organised with Directorate-General for Communications Networks, Content and Technology of the European

Commission. The Web Accessibility Directive, adopted in 2016, sets September 23, 2020 as the date by which all public sector websites across the EU must be accessible for persons with disabilities. So, the online event will mark this important milestone for digital accessibility and participation in the EU. The programme will be made available on the EDF's website very soon.

Key stakeholders will highlight achievements and remaining challenges in terms of practical implementation of web accessibility from different perspectives, including policy makers, Member States, activists, users, academia and accessibility professionals.

Register now and save your spot (places are limited). Please register through this link: <u>https://attendee.gotowebinar.com/register/8130383120502176781</u>. The online event will be public, free-of-charge, and recorded. International sign interpretation and live captioning will be provided.

Contact: Mher Hakobyan, EDF Accessibility Officer, mher.hakobyan@edf-feph.org



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

September 13 – 17, <u>2021</u> – International Conference for Pastoral Care among Hard of Hearing – IVSS Churchear

> Location: Haus Hainstein in Eisenach, Germany Information: <u>http://www.churchear.org</u> Contact: Barbara Adamus, board member Email: post@churchear.org



It is with heavy hearts that we postponed this year's International Conference for Pastoral Care among Hard of Hearing until next year. The new conference dates are September 13 to 17, 2021. The conference site remains the same.

A crisis is, however, even a possibility. This postponement gives us another year to contemplate what we want to achieve with our association in the future. The rapidly growing number of hard of hearing people makes IVSS Churchear more necessary than ever.

With kind regards on behalf of IVSS-Churchear Barbara Adamus, Board member

Read or download the latest newsletter from IVSS Churchear here.

News Bytes

HEAR-IT.ORG NOW AVAILABLE IN ITALIAN

Hear-it.org is a non-commercial web site and has been established to increase public awareness of hearing loss. Hear-it.org is a comprehensive website on hearing, hearing loss and tinnitus and how to treat and live with hearing loss or tinnitus. It is now available in Italian; you can find it here: www.hear-it.org/it.



STUDY SHOWS IMPROVEMENT IN SPEECH PERCEPTION FOR CIS

Hear-it.org reports that an Australian study showed that speech perception improves markedly within a few months for adult cochlear implant recipients with a severe or profound hearing loss. The study found rapid improvement in speech perception by the end of three months and continuing improvement over 12 months after the cochlear implantation. The study also found that the severe group had better speech perception than the profound hearing loss group after the cochlear implantation which may be explained by the severity of the pre-operative hearing loss.

In the study, the Sydney Cochlear Implant Centre (SCIC) database was searched for adults who had cochlear implant surgery between 2009 and 2015. A total of 1,751 adults were found in the database to have had surgery performed between 2009 and 2015. Patients were included in the study if they had a pre-operative four frequency average of profound hearing loss (90 dB HL and above) or a severe hearing loss (70- 89 dB HL). The study (Cochlear Implant Outcomes in Patients with Severe Compared With Profound Hearing Loss), was published in the journal Otology & Neurotology.



OCHLEAR MPLANT PROGRAM In RIDBC service

(Sources: Hear-it.org, <u>www.ncbi.nlm.nih.gov</u> and the journal Otology & Neurotology.

"CHEMICAL EARMUFFS" COULD PREVENT HEARING LOSS

A team of American biologists at the University of Iowa and Washington University say it may be possible to block in advance the negative effects of loud noises. The researchers have

identified a receptor that, when blocked, can prevent this common type of hearing loss. Receptors are part of a set of molecules on nerve cells in the ear that bridge the passage of sound and auditory information from innerear hair cells to the brain. The successful transmission of sound from hair cells to nerve cells, which occurs through a junction called a synapse, is integral to hearing in animals, including humans.



The researchers identified that some receptors involved in the hair-cell-to-nerve-cell transmission lack a protein called GluA2, and it is these receptors that are responsible for synaptopathy, or hearing loss caused by irreparable damage to the synapses.

The biologists employed a drug in mice that selectively blocked the GluA2-lacking receptors and prevented the mice from experiencing synaptopathy when exposed to noise. The approach is described as like putting chemical earmuffs on the mice. The study has been published in the journal *Proceedings of the National Academy of Sciences*. (Image credit: CCO Public Domain) **READ MORE**.

CANADIAN WOMAN WITH COCHLEAR IMPLANTS AT NATIONAL CURLING CHAMPIONSHIPS



Emma Logan was awarded a Ccholarship by the Canadian Hard of learing Association (an IFHOH general nember) in 2018.

Earlier this year, inspired by her fiveime Canadian champion aunt-and Nova Scotia teammate, Mary-Anne Arsenault, Imma has competed in the Canadian ational curling championship, the 2020 Scotties Tournament of Hearts.

The lead for the Canadian province of Nova Scotia is an inspiration to many others in the curling world as she became what is believed to be the first player with profound hearing loss to compete at the national championship. Emma lost her hearing when she was just 13 months old after having meningitis and now uses cochlear implants to help with her disability.

Help us thank our sponsors by supporting them

This issue features Amplifon!



Amplifon

the world's leading dedicated hearing aid specialist

With 60 years' experience and more than 5,700 specialist centres in 20 countries, we're the world's leading dedicated hearing aid specialist.

All our hearing care is tailored to each person's hearing and lifestyle needs and is delivered by professionally qualified hearing aid audiologists.

From our comprehensive hearing assessment to your programme of Free Lifetime Aftercare, we are committed to help you get the very best from your hearing.

IFHOH JOURNAL

The deadline for submissions for the next issue is <u>October 15, 2020</u>. **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



MISSED AN ISSUE OF IFHOH JOURNAL? LOOKING FOR AN ARTICLE THAT YOU REMEMBER CONTAINED USEFUL INFORMATION THAT YOU COULD USE?

You can find past issues of IFHOH Journal archived at: <u>https://www.ifhoh.org/journal</u>

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The International Federation of Hard of Hearing People (IFHOH) is an international nongovernmental 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

President, Dr. Ruth Warick (Canada) Vice-President, Avi Blau (Israel) Treasurer, Heikki Niemi (Finland)

General Secretary, Hanh Duong Phuong (Vietnam) EFHOH Representative, Marcel Bobeldijk (The Netherlands) Member at Large, Patrick Gift Egessa (Uganda)



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)