

European Federation of Hard of Hearing People







EFHOH Newsletter | December 2020



Dear EFHOH members and friends,

Warm greetings from the EFHOH board! 2020 is coming to an end and it has been one strange year for us all. This EFHOH newsletter highlights our main actions in 2020, but of course, by March our lives were turned upside down by COVID-19.

Despite this, there are many achievements to highlight from our work. Most notably we had to move our board meetings and the AGM 2020 online. We also added many online meetings and events, together with EDF and IFHOH, to help our members respond to COVID-19. IFHOH and their international partners issued a statement on accessibility during the pandemic which you can revisit here: https://bit.ly/3fizYUP

I am sure that we all have had some kind of experience related to COVID-19. I had my own experience as I was in isolation at the hospital for three days because the medical staff thought that I may have had the virus. The communication was mostly via an electronic communication system but before I went into the isolation room, I asked them to "please come into the room when you need to communicate with me because I am hard of hearing." All the doctors and nurses did just that and sometimes we had a talk via the glass door, or even by pen and paper. Only once was there some miscommunication via the electronic communication system as a nurse asked me if I would like a croissant for breakfast. I heard and understood the word "croissant", but it was too early in the morning for my brain. I was thinking, a croissant for breakfast in a Dutch hospital, that perhaps I heard it wrong. But it was correct and kind of funny. After three days, I received the news that I did not have the coronavirus but that I cancer so there was good news and bad news. Some weeks later, I had an operation at another hospital in Leiden, where they removed the tumor from my kidney. I am now in the recovery process and it is going fine. The results of the first checks were good so I can say that I am clear. Also, at this hospital, I informed each doctor and nurse that I was hard of hearing and that I wear hearing aids. All the doctors and nurses, therefore, knew that I was hard of hearing and they were friendly and helpful. So, my message to you is that it is always best to inform others that you are hard of hearing and what your needs are.

It is also what we learn in different workshops regarding coping skills and self-advocacy. I took it as my responsibility to inform all the great people in the hospital and I am glad that I did. I recommend that you do the same, inform others and let them know your needs. We as the

EFHOH board participated in different webinars and online workshops and have given presentations including the webinars about COVID-19 and CI organized by IFHOH. At the webinar about CI, our treasurer Darja was one of the speakers.

EFHOH's secretary Aïda was also one of the speakers at the LTA project event, where she gave a presentation about COVID-19. You can watch her presentation and the other LTA video presentations on their YouTube channel:

https://www.efhoh.org/lta-online-multiplier-event-videos/

A big thank you to Niels-Henrik Hansen for being the EFHOH news editor over the years. We wish him the best of luck in his new pursuits. He will be missed. We are excited to welcome Alper and Ece from Turkey as our new editors of the EFHOH newsletter. Some of you will know them from their days in IFHOHYP. Welcome to EFHOH! Also, a warm welcome to Freda from Ireland. She will write a column for the EFHOH newsletter. Thanks, Freda! Of course, your feedback and articles are more than welcome.

Some last news about the EFHOH AGM 2021. As EFHOH board we came to the conclusion that related to COVID-19, an online meeting in the spring of 2021 is the only possibility and we have found a date for the online EFHOH AGM 2021, which is 19 of May 2021 and the time is from 19:00 to 21:00 (Amsterdam time). More information and details will be sent in January 2021 to our members and published on our website.

Dear All,

On behalf of the EFHOH board and our volunteers, I wish you all, together with your family and friends, a Merry Christmas and a Happy 2021! I hope to see all of you at one of the online meetings or our online AGM 2021.

Enjoy reading the new EFHOH newsletter and stay safe and in a good health.

Warm greetings,



Message from IFHOH

Dear Friends,

A major preoccupation for many of us is the continuing impact of the COVID-19 pandemic given the strength of its second wave. Unfortunately, it is not safe for large gatherings to be held and this impacts the IFHOH World Congress. Originally scheduled in May 2020 with our European partner, SINOSZ, our hopes to reschedule to spring 2021 are being dashed by the continuing pandemic. Please be assured that we will communicate any new plans as soon as they are finalized.

The pandemic is impacting us in other ways including increasing difficulties with communication due to social distancing and the wearing of covered masks. There are economic and social impacts as reported in our survey on the subject with IFHOHYP, EFHOH and our Asia-Pacific region; the survey results are on our website at www.ifhoh.org.

Increasingly, more activities are being offered on-line and IFHOH had its first webinar in August; we focused on the impact of COVID-19. A second webinar was offered in October about cochlear implants and we are pleased to be offering the third webinar on project findings related to Inclusive Education in Uganda and Nepal. The webinar will be held on 30 November 2020 at 5 pm CET. To register go to

https://uso2web.zoom.us/meeting/register/tZErd-yvqjkuHty-wFB1k5jz_JGcXiiCJvtm.

Please note that for those unable to attend the webinars, we are posting the links to them on our website so you can view them at your convenience. As well go to our website for updates on upcoming webinars.

We will also be offering further webinars in the coming months, including a follow-up webinar on cochlear implants as a result of feedback requesting more such events. We also plan a webinar about our policy paper on Cochlear Implants which we are revising to update and to take into consideration the recent adoption of publication of an International Consensus Paper on CI Clinical Practise.

Another webinar will focus on the upcoming World Hearing Day and the release of the World Report on Hearing on 3 March 2021. This landmark report could be used as a catalyst for change. We urge organizations to plan an activity for World Hearing Day related to its theme of Hearing Care for ALL and to identify priority hearing health care issues in their country for attention. We will be developing a summary of some activities for your consideration, such as developing an advocacy plan around the World Report on Hearing. Together with EFHOH, we look forward to maximizing the impact of the World Report on Hearing for the benefit of our communities.

In other news, we continue to be actively involved with the International Disability Alliance and are pleased to be able to take part in their Fellowship Programme for the first time. The Fellowship focuses on employment issues in a specific country as designated by IDA. I am pleased to announce that we were able to award two Fellowships after a juried competitive process, and the recipients are Brender Wanyana and Moses Serwadda in Uganda. Both will be engaged until the end of June and will provide a report and webinar about their work.

I invite you to connect with me should you have any suggestions or questions.

All the best,
Ruth Warick
IFHOH President
president@ifhoh.org





Panel 2

Moderated by Catherine Naughton, EDF Director

Hector Minto, Microsoft, Sr. Technology Evangelist, Accessibility – work

Courtney Craven, Can I Play that? Editor-in-chief - videogames

James Thurston, G3ICT, Vice President for Global Strategy and Development – digital public services









New building standard important for hard of hearing people

The first European Standard on Accessibility and Usability of the Built Environment, EN 17210, has now been adopted after a lengthy process and has been given November 30 2020 as the day of ratification.

This standard is very important for persons with disabilities, as it aims to contribute to the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) in Europe and ensure that persons with disabilities, older person and persons with functional limitations are able to access the outdoor and indoor built environment on an equal basis with others.

The new standard is designed to be used in public procurement but could also be used in the private sector. Since the built environment is not regulated at EU-level, it will not be mandatory, but national standards must be revised in line with EN 17210. The standard describes basic, minimum functional requirements, and recommendations for an accessible and usable built environment, following "Design for All"/"Universal Design" principles.

For hard of hearing people, there are important features such as alarms must always be both audible and visible; auditoriums, arenas, receptions, and classrooms shall always have loops or equivalent hearing enhancement systems, and the importance of good acoustics is highlighted.

Digital accessibility expands with the pandemic

The COVID-19 pandemic has boosted the use of online tools, and hard of hearing people are by no means an exception. But we meet special challenges – we need clear, crisp sound, we need to see the face of the person speaking – and we love it when there is live subtitling. To learn more and discuss new accessibility features EFHOH board members took part in the webinar "Rolling out accessibility" arranged by EDF in cooperation with tech companies on October 29.

María López Carracelas, Facebook EU Public Policy Manager, presented the last accessibility features of social media, such as automatic alternative text, including for actions, and the possibility to add captions also in live streaming.

Hector Minto, Senior Evangelist of Accessibility at Microsoft, reviewed their main tools and accessibility features, which use has increased exponentially for the past months. Microsoft video platform Teams have live text created by ASR (Automatic Speech Recognition) in a number of languages.

Gion Linder, Head of Access Services at the European Broadcasting Union shared the results of a survey on access services conducted in 43 public broadcasters from 28 countries in 2019. 83% of channels provide live subtitles to some extent.

Read more and take part in the presentations:

<u>http://www.edf-feph.org/newsroom/news/rolling-out-accessibility-technology-great-ally-inclusion-persons-disabilities-all</u>

Alf Lindberg EFHOH Board Member





The corona pandemic presents major challenges but also new opportunities.

Infection situation with regard to covid 19 presents us with great challenges and it is important to follow the health authorities' recommendations on how you and those around you can stay healthy and contribute to infection control. Due to the coronary pandemic, HLF(Hard of Hearing organization in Norway) has also had to reduce its activities. In line with the health authorities' recommendations, all HLF's courses and activities are extremely limited and we work to create good digital solutions. Unfortunately, the infection situation also affects HLF's voluntary hearing peers. This means that our hearing peers must guide and assist via e-mail, telephone and SMS and that HLF advises against outreach activities and open offices in public places. Home visits should only be made to take care of life and health. In such situations, the health authorities' order for protective infection measures must be followed in order to safeguard all hygiene considerations, and we encourage everyone to contribute to the national effort to limit the spread of coronavirus. Care and maintenance of hearing aids are therefore to a greater extent left to the individual, family members, or others. On HLF's websites, we have made subtitled self-help videos that can be used. HLF also made a separate transparent mask for our members where oral reading is possible.

Cochlear Implants: Increasing Awareness and Advocacy

In October, a webinar entitled Cochlear Implants: Increasing Awareness and Advocacy was organized by IFHOH in close collaboration with EFHOH. The purpose of the webinar was to present the International Consensus Paper, the process of its creation, and the importance and minimum standards of care for adults with severe to profound hearing loss as well as users' views and experiences.

The first part of the webinar focused on the creation of the whole process of the International Consensus Paper. It is extremely important that people with hearing loss can participate in the creation of such an important document with their views, knowledge, and experiences. The second part was focused on the users' experience and I have to say that it was interesting for me to prepare a contribution from a user's point of view.

Throughout the webinar, there was also a lively discussion in the background with various issues and there is a huge interest to continue collaborating. In my opinion, it certainly portrays how strongly the community of people with hearing loss is actually linked at the international level, and how the roles of organizations are of paramount importance in terms of raising awareness and sharing experiences.

Speakers on the webinar 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

A second webinar is planned for December and we hope to see you there! You can watch the whole webinar here.

We have been familiar with CI implants for several years and the number of CI users is gradually increasing. At various meetings held in recent years between people with hearing loss, users of both HA, CI, manufacturers, and the medical profession, there was an initiative to form an expert group that will reasonably unify the criteria for determining the criteria for implantation worldwide. The fact is that when a certain degree of hearing loss occurs, the hearing aid no longer serves its purpose and the implantation is recommended.

However, implantation programs vary from country to country and are highly dependent on understanding what implantation means to both the individual and society at large.

Thus, in 2018, an extensive questionnaire was designed and processed in accordance with the Delphi method. Delphi consensus is an established technique, which reaches the consensus of a group of experts by the collection and aggregation of their informed judgments.

It is very important that a group of representatives from international cochlear implant users and professional advocacy organizations (CAPAC) was involved in the development of the consensus statements. The CAPAC was formed to ensure the patient's voice was considered in the Delphi consensus process.

In 2019, the document of Adult CI Standards of Care to improve

referral pathways and treatment was prepared - Delphi Consensus Process paper was published in 2020. An International Standard of Care provides expert guidance on improved referral pathways and consistent clinical guidelines for the treatment of severe to profound sensorineural hearing loss. The document was published in JAMA Otolaryngology: Unilateral Cochlear Implants for Severe, Profound, or Moderate Sloping to Profound Bilateral Sensorineural Hearing Loss; A Systematic Review and Consensus: Delphi Consensus Paper.

With international guidelines on adult cochlear implants, an attempt was made to provide more uniform options for individual candidates for CI and an explanation of the treatment procedures.

As a result of the whole procedure, the adulthearing.com website was created, and the page presents itself as "a professional education platform that aims to increase awareness through the latest clinical evidence to reach an agreed standard of care for adults with hearing loss."

In the past 2 years, EFHOH participated in the process with its user experiences and knowledge.

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Rolling out accessibility. Technology as a great ally for the inclusion of persons with disabilities in all aspects of life

The whole of Europe is currently experiencing a second wave of COVID-19 infection, even stronger than in March. Equal access to technology is essential to avoid isolation and to improve the inclusion of persons with disabilities.

Thanks to the sponsorship of Facebook and Microsoft, last Thursday 29th October EDF held the webinar "Rolling Out Accessibility" in which, thanks to all our panelists, we discovered a range of popular



online tools and services and how they are becoming more accessible for persons with disabilities.

We are happy to point you to an <u>article</u> <u>summarising the workshop</u> and including the presentations from our panelists.



COVID - 19 and Hearing Loss in Ireland

At the Beginning:

Just before St Patricks Day (March 17th) we were put into lockdown for a few weeks. This meant that we had to stay at home and those of us that were considered "vulnerable" were "cocooned". No visitors, no leaving the house. Food had to be brought to us. We had family members who did the shopping for us.

For exercise, we, in this house, did a few exercises that were posted, the main one being to walk up and down the stairs ten times a day! The huffing and puffing doing this made us laugh and I actually only did five sets twice a day.

The hair grew and grew. We baked cakes to keep occupied and unfortunately put on a lot of weight!

The television was a distraction BUT, for one cocooner, was frustrating as subtitles are not perfect in Ireland. When I complained to the broadcasting station I was told that the subtitles were actually very good!!!

Lightening the restrictions:

We were allowed to go out for walking exercise but within 2 kilometers of the house. This was later increased to 5 kilometers from the house.

A major birthday celebration (dinner, bed and breakfast) booked in a rather nice hotel had to be cancelled in early May for 10 adults and 11 grandchildren! The alternative was a super day in our back garden in glorious sunshine and our four families came separately (mixing of families forbidden) each bringing a birthday cake and candles. We distanced and the children played their musical instruments for us and one group played football! The two seniors left in the house at the end of the day enjoyed a Thai Takeaway meal and were in bed and asleep by ten o'clock!!

Shopping was still carried out by the nearest son as the rest of our family were outside our county and not allowed over the border. Hospital appointments happened and that was when I discovered that I could not understand ANYONE wearing a mask.

I had a couple of appointments and explained my needs. One nurse said she wasn't allowed to remove her mask (fair enough) and I asked for other nurses until I met one who's speech I could understand through the mask. We have many excellent non-Irish people working in this country so a foreign accent is difficult even without a mask.

I was able to get a hair dressing appointment and had to wear a mask throughout the procedure! My hairdresser was very kind and lifted his mask when he spoke to me in the mirror! I had two hair cuts before the final lockdown "Level 5" of six weeks so I am pretty rugged these days!

We had to cancel two holiday breaks due to the virus but were able to take three of our grandchildren to our favourite place in County Mayo for three nights in August. The weather was atrocious but that's Ireland for you!

HOH social side: (in Dublin)

The National Gallery of Ireland, for many years conducted a HOH guided tour every second month and we had neck loops or headphones to follow the guide throughout the tour. This was a great social outing and we met beforehand and some of us continued into the night! The Hugh Lane Gallery followed suit early this year and was also very popular with a local cafe nearby which most of us retired to after the tour. UNFORTUNATELY this came to a stop in March with the first lockdown.

I had been meeting up with a small group of HOHs for a meal once a month (we talked loudly and the neighbouring tables listened in but we didn't mind) and we went together to the captioned cinema but that all ceased before Level 5 started as we began to feel afraid of the virus.

Level 5: (20 October)

This was/is six weeks of the following

Social and family gatherings

No visitors to home or garden, with the exception of visits for essential purposes (for example: family reasons such as providing care to children, elderly or vulnerable people, or as part of a support bubble).

Other settings outside your home or garden

It is possible to meet with 1 other household in an outdoor setting which is not a home or garden, such as a park, including for exercise.

No other social or family gatherings should take place.

The six weeks finish early December and we wait to see what restrictions might be relaxed for the Christmas period.

We have not been able to see our grandchildren during this time except on Video calls or Skype.

Google Meet has been used by me to get subtitles at the bottom of the screen but needs a lot of care to keep one person talking at a time (and not all together which is normal for kids)!

Christmas 2020

We will learn about what we can expect in the next few days. We hope to be able to hug our small people for Christmas at least once.

I hope to be able to report a happy if restricted Christmas in the New Year.

HAPPY CHRISTMAS to everyone in EFHOH.

Freda







News from a member of ASIA PACIFIC FEDERATION OF THE HARD OF HEARING AND DEAFENED (APFHD) -Center for Research and Education of the Deaf and Hard of Hearing (CED), Vietnam

Some news from CED, Vietnam in the COVID pandemic

- Granting 56 hearing aids for 31 children and adults with hearing loss (16 Males and 15 Females) since January 2020. CED calls for hearing aids donations and for further information, please contact Ms Hanh: dphanh@trungtamkhiemthinh.org or hanhdpvl83@gmail.com
- In collaboration with the Vietnamese American Scholarship Fund (VASF) and Center for the Encouragement of Self-Reliance (CESR), granting 12 scholarships for 12 students with hearing loss who live in difficult circumstances and study at CED. The scholarship value is 65 USD per month and applied to the school year 2020 2021.
- In collaboration with the BUI Art to organize an exhibition of paintings drawn by Hard of Hearing students of CED. This exhibition collected USD 1,000 for CED.
- Successfully calling donations/scholarships from Signa (by Quang Duc Hearing Services Company) and EasyHear (by KindHeart Hearing Service Company) for students with hearing loss whose parents are unemployed by the COVID. Each scholarship value is USD 500.
- 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)".

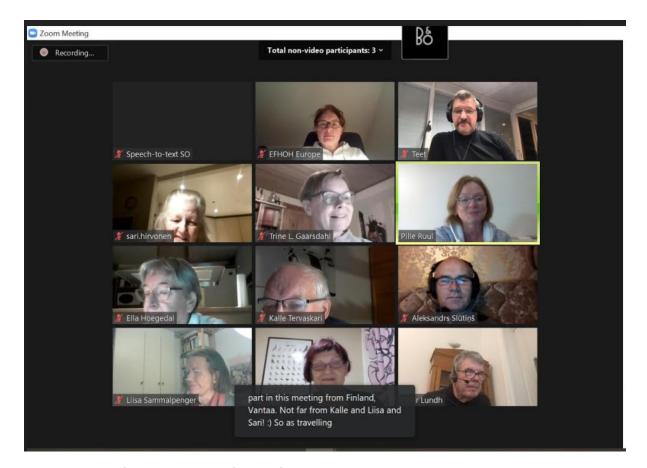
This project aims to support people with hearing loss in Ho Chi Minh city to access public medical services in the contexts of patient visiting and of medical examinations, as well as to support some hospitals to meet the Hospital Quality Criteria, version 2.0 (issued together with Decision No. 6858/QD-BYT,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



VDNR -- virtual meeting via Zoom

VDNR* had a Zoom meeting in November about the questionnaire regarding STT interpretation in the Nordic and Baltic countries. Darja Pajk was the moderator of the meeting and represents the European Federation of Hard of Hearing People.

It was VDNR's first virtual and successful meeting. We are not finished with the discussion about the questionnaire regarding STT interpretation, because we are missing the last 10 questions and discussion about the VDNR annual meeting and seminar in Copenhagen in May 2021.

We have a second virtual meeting in January to conclude the questionnaire and discuss the annual meeting. We look forward to that.

*VDNR – Nordic Council of Late-Deafened (Original name in Swedish: Vuxendövas Nordiska Råd)

D. 25. November 2020, Trine Lindhardt Gaarsdahl, Chairman of VDNR.



EFHOH is a proud partner of LTA project

The LTA project is a 3-year Erasmus+ project, aiming to build up education for Speech To Text Interpreters (STTIs) / subtitlers be it typing on a keyboard or respeaking to enable accessibility via text on spoken information for the Hard of Hearing population. EFHOH is a partner in this project, and we are proud partners.

From EFHOH we contribute in particular on topics like hearing and hearing loss, audiological treatment as well as users' perspectives on accessibility and multimodality.

We are now in the 3rd year of the LTA-project https://ltaproject.eu and towards the end also on developing teaching and information material as well as the final exams for the online course for STTIs/subtitlers.

There was meant to be a symposium in Barcelona over summer 2020, but related to COVID-19 this was not possible.

Instead, the project had an online symposium on Thursday 5th November and an LTA-event on Friday 6th November. Just for the LTA-event on Friday 6th, there were over 200 attendees from all over the World.

We are able to share with you a link to the presentations from Friday 6th November, which is on the LTA YouTube channel: https://www.efhoh.org/lta-online-multiplier-event-videos/

We would also like to share with you this article on the inclusion of persons with hearing loss in live contexts through real-time intralingual subtitles, in which Dr. Rocio Bernabé Caro, who leads the project, explains more about the aims and need for this Erasmus+ project.

https://www.efhoh.org/wpcontent/uploads/2020/11/1LiveTextAccess_SDI-Muenchen_EFHOH_final.pdf

What's New on the EFHOH Website?

On the EFHOH website, you can find some new additions such as Hearing Health Info., where we have shared the translated texts of Stein Thomassen from his popular Norwegian blog on hearing loss. In the Campaigns section, you can also find an online hearing test offered through our partners at Hear-it.org. Board meeting minutes held over the past months are available in the For Members, Members Only section. As always, you can find the latest news about EFHOH and our partners @ https://www.efhoh.org.

Are public sector bodies' websites accessible?

Check out our website for the <u>video of the online event</u> we coorganised with the European Commission on <u>23 September</u>, the deadline for all public sector websites to comply with the Web

Accessibility Directive.

We want to know if websites of the public sector are progressing on digital accessibility. We would be grateful if you could disseminate this <u>survey</u> (available in English, French, and Spanish) among persons with disabilities to get feedback.

<u>Link to the video</u>.

<u>Link to the summary of the event</u>.

<u>Link to survey</u>.

Contact: <u>alejandro.moledo@edf-feph.org</u>

And the winner of the Accessible Airport Award is...

As part of a Memorandum of Understanding signed by <u>ACI</u> <u>Europe</u> and the European Disability Forum (EDF) in 2016, the Accessible Airport Award honours the best airport in Europe in terms of its level of accessibility as well as the range and the quality of the assistance services offered. It is also intended to encourage other airports to continue their work on removing the barriers that people with disabilities and persons with reduced mobility (PRM) can still face when travelling by air.

This year's Accessible Airport Award went to Copenhagen Airport.

Find out why Copenhagen Airport won the Accessible Airport Award.

Mail to: <u>office@efhoh.org</u>
Visit our website at <u>www.efhoh.org</u>