



IFHOH JOURNAL

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v3

IFHOH President
Dr. Ruth Warick
president@ifhoh.org

Journal Editor
Carole Willans
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 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 Interim General Secretary

Dear IFHOH friends,

While the COVID-19 pandemic does not respect boundaries, access to vaccines stops at the border between countries. The [Our World in Data](#) website, created by the Oxford Martin School of the University of Oxford, monitors statistics on COVID-19, including the global vaccine rollout. Israel is the global leader at vaccine rollout. The other most efficacious countries at vaccine rollout are: United Arab Emirates, the United Kingdom, the United States of America, Denmark, Iceland, Italy, Slovenia, Canada, and Estonia.

The rollout of COVID-19 vaccines in developing countries is critical to protecting lives, building human capital, and stimulating economic recovery. The pandemic is worsening inequalities throughout the world and, without access to vaccines, the gap will widen further. This thought makes me sad. Ensuring developing countries can access and safely distribute vaccines, calls for strong partnership and cooperation at the national, regional, and global levels. Despite the efforts of the World Health Organization and other international groups, it is difficult to awaken the political will of the governments of developed countries to make a significant contribution outside their own borders.

There is however one bright light resulting from the pandemic - the rise of telehealth services. It is gaining ground in both developed and developing countries. Its rise was already happening before the pandemic, and it is growing exponentially because of the need to keep our distances as well as many other factors that can be linked to the pandemic. Telehealth can really help improve hearing health care in the developing world. This will only be achieved by raising awareness, understanding, and ability regarding telehealth capability and limitations, and by the coordinated political and professional will of all those involved to guide public and private innovation and telehealth integration. Read more on this important topic in this issue. It is part of the future for all of us.

Please continue to be careful, whether you have been vaccinated or not. Ensure your safety and that the others around you.

- Carole

IFHOH President's Message



Ruth Warick

Dear Friends,

We have endured the social isolation of the coronavirus pandemic for over a year, both personally and as an organization. But there is much to celebrate, and it is important that we treasure our roots.

Congratulations to the Swedish Association of Hearing Impaired Persons (HRF) for celebrating their 100th anniversary this year, a milestone achievement. IFHOH was founded in Stockholm in 1977 with HRF as one of its founding members. IFHOH has been blessed by having former leaders from Sweden including Lars Lindén and Jan-Peter Strömngren. Lars was President from 1988 to 1992, and Jan-Peter held this office from 2006 to 2010. In addition, Bengt-Ake Leijon and Ulf Olsson served on the IFHOH board previously.

The Swedish Association was also the host for the 1984 IFHOH World Congress, as well as for the IFHOH Biennial General Meeting in 2010. I had the opportunity to attend the 1984 Congress, my very first one. Little did I know that this would be the start of my involvement with IFHOH. It was a bit of an adventure getting to Stockholm as I received a free plane ticket only two weeks before the start of the Congress. I had to obtain a passport and organize travel plans to the airline's destination point in Europe (Frankfurt). From there I traveled by train, day and night, through Germany and Denmark to Stockholm. The journey was worth this experience of a lifetime.

Congratulations are also in order to the new board of EFHOH which was elected at its recent online AGM: Lidia Best, President; Jennie Westh, General Secretary, and Darja Pajk, Treasurer. They join existing officers Morten Buan, Vice-president, and Alf Lindberg, Member at large.

Our thanks to the retiring board members of EFHOH, Aída Regel Poulsen and Marcel Bobeldijk. As well, this marks the conclusion of Marcel's tenure as an IFHOH board member representing EFHOH as its President. He has served in this capacity since 2003, a remarkable record of service.



Ulf Olsson of Sweden and Marcel Bobeldijk, shown at IFHOH Board meeting held in Stockholm

Also retired from the IFHOH Board is General Secretary Hanh Duong Phuong. Her service on the board for four years was much appreciated. Carole Willans, editor of the *IFHOH Journal*, has been appointed as interim General Secretary until elections are held at the next IFHOH BGM.



Ruth Warick and Hanh Duong Phuong at IFHOH Congress at HLA (Photo by Siegfried Karg)

We ask that you reserve the dates of 10-12 March 2022 for the BGM and IFHOH Congress, previously postponed from May 2020 due to the pandemic. We look forward to the event, being organized by our Hungarian partners, SINOSZ, in Budapest. Further details and the unveiling of the website will be shared in the coming months.

In immediate upcoming events, please hold the date of 22 June 2021 for a webinar by the International Hearing Access Committee (IHAC) on *The Future of Hearing Loops and New Technology*, as noted within this issue. In this session, members of IHAC will discuss the role of the telecoil and the status of future technological developments, including Bluetooth LE Audio and HearStream.

In other IFHOH news, we have revised the design of our monthly Bulletin, and hope that you like the new look. All member organizations are on our mailing list plus individuals who request to be added; a request can be made to info@ifhoh.org.

We are revising our policy paper on cochlear implants and have scheduled a webinar on it for May 31. The paper is being updated to reflect a strong consumer voice as framed in 10 recommendations for this important but under-utilized technology. Thanks to Bowen Tang, President of the International Federation of Hard of Hearing Young People, and Carole Willans for working with me on the revised paper, available at www.ifhoh.org/position-papers. Please review it and share your thoughts with us.

Our position paper on Hearing Accessibility Guidelines is also under revision, led by Vice-president Avi Blau. A webinar was held early in May in which various components of the paper were discussed and panelists shared their experience with technology. The paper is designed as a guide for those who want to know more about how to make their events and practices hearing accessible. It is also available on the IFHOH website.

A third paper is being newly developed, namely, a document pertaining to the WHO *World Report on Hearing* which was released on 3 March 2021. The report is an important advocacy tool for our community with respect to hearing health care, including prevention of hearing loss, hearing screening for persons of all ages, affordable and quality hearing aids and cochlear implants, and captioning. Meanwhile, please join with us in promoting a pledge to support hearing healthcare with the hashtag of **#Hearingcare**. It is on the IFHOH Facebook page: www.facebook.com/groups/IFHOH/.



With warmest regards
Ruth Warick
IFHOH President, president@ifhoh.org



UPCOMING IFHOH WEBINAR

Cochlear Implants: Reframing our Advocacy Statement

Cochlear Implants are recognized as proven technology that improve hearing access for countless persons. IFHOH has long been in support of cochlear implants as reflected in its policy paper developed in the mid-1990s. The paper is being updated given the recent release of the *World Report on Hearing* and the *Consensus Paper on CI Treatment for Adults Hearing Loss*. This session will be a discussion focusing on the issues that should be covered in the policy paper from a consumer-based approach. The revised paper covers topics of access, benefits, informed decision-making, and best practises. The revised paper will be posted on IFHOH's website www.ifhoh.org.

Speakers for the session are:

- Bowen Tang, CI user and President of the International Federation of Hard of Hearing Young People (IFHOHYP)
- Carole Willans, CI user and Interim General Secretary of the International Federation of Hard of Hearing People (IFHOH)
- Dr. Ruth Warick (Ph.D.), President of the International Federation of Hard of Hearing People (IFHOH)

Date: Monday, 31 May 2021

Time: 7 am PDT (Pacific Time), 10 am EDT (Eastern Time), 4 pm CEST (Central Europe Time),

Duration: 90 minutes

Register in advance at: https://zoom.us/webinar/register/WN_Bf5p_p-3TfC08IXeuViM7Q

After registering, you will receive a confirmation email. Realtime captioning will be provided; International Sign Language is available on request (deadline for request is 22 May).



Dr. Ruth Warick



Bowen Tang



Carole Willans

UPCOMING IHAC WEBINAR

The Future of Hearing Loops and New Technology



The death knell of telecoils has been rung on more than one occasion in the last decade, but are these reports credible? The telecoil, has long been an essential feature of hearing aids and cochlear implants that increased hearing access and, therefore, an individual's quality of life. Today, access to a the telecoil means enjoying a theatrical production, comprehending a church sermon, or understanding a receptionist when a facility offers hearing loop or FM/IR technology with neck loops or a built-in counter loop. It means hearing on the phone when the latter is hearing aid compatible.

Technological developments are moving forward and recent developments of LE Audio and HearStream, a wireless network, promises to supplant the need for the telecoil in the future, though its implementation timeframe is unknown. The International Hearing Access Committee issued a statement in 2020 recommending caution be exercised about the demise of the telecoil while supporting advances. "The rights of HA/CI users to access must be continued and maintained during this period of technological change and shall not be compromised by the promise and overly optimistic expectations of a future technology development."

In this session members of IHAC will discuss the role of the telecoil and the status of future technological developments including Bluetooth LE Audio and HearStream. (IHAC is a committee involving those presenting and moderating in this webinar.)

Panelists:

- Aïda Regel Poulsen, European Federation of Hard of Hearing People (EFHOH)
- Avi Blau, International Federation of Hard of Hearing People (IFHOH)
- Dr. Juliëtte Sterkens, Hearing Loop Advocate of Hearing Loss Association of America (HLAA)
- Dr. Rob Drullman, Secretary of the Technical Committee of the European Hearing Instrument Manufacturers Association (EHIMA)
- Andrew Thomas, Chairman of IHAC and of the International Hearing Loop Manufacturers Association (IHLMA)

Moderators: Hannes Seidler, Hearing Loss Association of Germany, and Ruth Warick, IFHOH

Date and Time: 22 June 2021, for 90 minutes at 7 am PDT, 10 am EDT, 4 pm CEST

Please register by 18 June 2021: https://zoom.us/webinar/register/WN_4iFHiqyqR2ayEOygvx83Mg

The session will be captioned in English. International sign language interpreters can be required on request to be made by 8 June 2021.



IFHOH Webinar on Hearing Accessibility Guidelines

On 6 May 2021, IFHOH presented a webinar based on the new IFHOH position paper entitled: *Hearing Accessibility Guidelines - for Hard-of-Hearing Persons and for Event Organizers*. Here is the link to the position paper: [Hearing Accessibility Guidelines](#). Over 60 participants attended the webinar, representing more than 30 countries.



The term "hearing accessibility" includes a broad range of measures that can improve the ability of persons who are hard of hearing to hear and communicate better, and to participate more fully in auditory-based activities. Measures range from well-fitted hearing aids to good room acoustics and lighting, and assistive listening devices or systems (wireless communication systems such as hearing loops, infra-red, FM, and Bluetooth systems). Training in speechreading would also be another useful course of action when it is available. Safety measures adapted to persons with hearing loss, such as vibrating alarms and flashing lights, are also part of hearing accessibility. There was much discussion about captioning, which are considered very important for accessibility; the presenters discussed the fast improving, artificial-intelligence based, automatic-speech-recognition for captions.

Many of the questions and comments of participants focused on the very different situations in terms of hearing accessibility in different parts of the world. It clearly emerged that while there is a broad array of options, they are not available to everyone. Participants agreed that we still have a very long way to go, especially in developing countries.

Marcel Bobeldijk, President of EFHOH, served as moderator. The speakers were:

- Aida Regel Poulsen - General-Secretary of EFHOH - *Hearing accessibility in Europe*
- Muhammad Akram - Former Secretary-General of APFHD - *Hearing accessibility in Asia-Pacific*
- Rocio Bernabé - Internationale Hochschule SDI München - *Live Text Access (LTA) implications and update*
- Avi Blau - Vice president of IFHOH - *Hearing accessibility, new developments*
- Ruth Warick - President of IFHOH - *Overall Summary*

Members will be advised when a recording of the webinar becomes available.

WHO Webinar on Telehealth Services



Is Telehealth accessible for people with disability?

The difficulties experienced by persons with disabilities accessing and using telehealth services (also known as telemedicine or eHealth) was the topic of the *WHO-IDDC Seminar on Accessibility of Telehealth Services* held 25 March 2021.



Dr. Alarcos Cieza, seminar moderator (WHO)

The current COVID-19 pandemic has raised the profile of telehealth services. Current experiences have revealed that many people with disabilities are met with obstacles while trying to access and use telehealth services. These obstacles are likely to persist after the pandemic unless action is taken now to address these obstacles. That is why the World Health Organization (WHO) and the International Telecommunication Union (ITU) have initiated the development of a global standard for accessibility of telehealth services. The seminar organized last March by WHO in collaboration with the International Disability and Development Consortium (IDDC) was an opportunity for over 100 participants to increase their understanding of the relevant issues, to discuss the challenges, and to outline concrete solutions that healthcare providers and manufacturers of telehealth platforms need to implement to make telehealth services accessible.

The WHO defines telehealth as the "delivery of health care services, where patients and providers are separated by distance. Telehealth uses information and communication technologies (ICT) for the exchange of information for the diagnosis and treatment of diseases and injuries, research, and evaluation, and for the continuing education of health professionals. Telehealth can contribute to achieving universal health coverage by improving access for patients to quality, cost-effective, health services wherever they may be. It is particularly valuable for those in remote areas, vulnerable groups and ageing populations. "

The Fifty-eighth World Health Assembly in May 2005 adopted Resolution WHA58.28 establishing an eHealth strategy for WHO. The resolution urged Member States to plan for appropriate eHealth services in their countries. That same year, WHO launched the Global Observatory for eHealth (GOe), an initiative dedicated to the study of eHealth. Its role is to review the benefits that ICT can bring to health care. It determines the status of telehealth services at the national, regional, and global levels, and provides Member States with reliable information and guidance on best practices, policies, and standards in telemedicine.

During the seminar discussions, it became clear that while there are many commonalities, people from developing countries are more likely to consider resource issues such as costs, underdeveloped infrastructure, and lack of technical expertise to be the key barriers to telehealth services, while people in developed countries are more likely to consider legal issues around patient privacy, competing health system priorities, and a perceived lack of demand to be the obstacles to its success.

Telehealth/telemedicine can take many forms, including live 2-way communication between patient and health provider in real time, remote patient monitoring and transmitting information to a health provider, store and forward (health providers share images and videos of health information with a specialist), and mobile health in health practice and education. There are many applications.



Dr. Kaloyan Kamenov

WHO technical officer and researcher Kaloyan Kamenov spoke on his study aimed at obtaining evidence on the availability of ear and hearing care (EHC) professionals to showcase the workload they face. With data on otolaryngologists from 138, audiologists from 102, speech and language therapists from 124, and teachers of the deaf from 86 countries, this study revealed large gaps in availability of EHC professionals. Most countries in the African region had less than one professional in each cadre per million in comparison with most European countries having up to 50 times higher densities. There is an enormous shortage of EHC professionals and urgent actions are needed to ensure sufficient and equitable access to services.

Task sharing is one approach, and telehealth hearing care is another major strategy that can greatly help overcome the shortage of highly qualified providers in many settings.

You can watch the seminar in full, with captioning, here:

IFHOH continues to participate in consultations and raise awareness globally with respect to the specific needs of hard of hearing people in the quickly changing world of telehealth services.

[Watch the seminar](#)

Disability Considerations for COVID-19 Vaccination

On 19 April 2021, the World Health Organization (WHO) and UNICEF published a joint policy brief entitled: *Disability Considerations for COVID-19 Vaccination*. IFHOH was among the international disability organizations that were consulted on the document. You can find the document at this link: <https://www.who.int/publications/i/item/who-2019-ncov-vaccination-and-disability-policy-brief-2021.1>

The policy brief is based on the [WHO SAGE roadmap for prioritizing uses of COVID-19 vaccines in the context of limited supply](#) and [Guidance on developing a national deployment and vaccination plan for COVID-19 vaccines](#).

The International Disability Alliance (IDA) was involved and feels the document "recognises that persons with disabilities are disproportionately impacted by COVID-19, and recommends that governments consult with persons with disabilities, their support networks, and representative organisations when implementing vaccination programmes. There is CRPD-consistent language on accessibility, data collection, training of staff, and on recruiting persons with disabilities as staff for vaccination programmes. There is a section on free and informed consent, which explains how health workers should ensure they have full and informed consent from a person with disability prior to providing the vaccination."



"Perhaps most importantly, the briefing recommends that governments: *Consider persons with disabilities according to WHO guidance when prioritizing sociodemographic groups for initial phases of immunization. Prioritize older persons with disabilities and persons with disabilities with relevant underlying health conditions according to WHO guidance. Consider staff working for disability support services when prioritizing frontline workers in health and social care settings in the initial phases of immunization*".

Overall, IDA regards this document very positively - it contains the fundamental elements of what a disability-inclusive COVID-19 vaccination programme might look like, addresses a comprehensive range of stakeholders, and incorporates CRPD standards to a higher level than has previously been the case with some WHO documents.



EFHOH News

The European Federation of Hard of Hearing People (EFHOH) held its Annual General Meeting (AGM) on 19 May 2021, shortly after the deadline for this edition of *IFHOH Journal*. Here is the link to the presentation of IFHOH President Ruth Warick at the EFHOH AGM: <https://youtu.be/zojAr5BMHZw>. The new EFHOH Board members are: President, Lidia Best (England)
Vice President, Morten Buan (Norway)
Secretary General, Jennie Westh (Denmark)
Treasurer, Darja Pajk (Slovenia)
Board member, Alf Lindberg (Sweden)

At the AGM, Ruth Warick expressed thanks to the outgoing EFHOH President Marcel Bobeldijk (who served as President since 2003) and Aïda Regel Poulsen (who served as their General Secretary for 6 years). She also congratulated Lidia Best on her new position and stated that the IFHOH Board looks forward to working with her.

Farewell Video



Marcel Bobeldijk

Marcel Bobeldijk (President) and Aïda Regel Poulsen (General Secretary), have both stepped down from the EFHOH Board of Directors. In preparation of this, they published a "farewell video", in which they are interviewed by Alf Lindberg (Board member, Sweden).



Aïda Regel Poulsen

You are invited to view this very interesting and informative video using this link: <https://www.efhoh.org/farewell-interview-marcel-aida/>. It provides a wonderful review of Marcel's and Aïda's tremendous contribution to improving the lives of hard of hearing persons in Europe and around the world.

European Disability Forum (EDF)

The EDF is preparing two important online events to be held very soon. On 27 May 2021, the EDF Conference on Rail Accessibility will take place, followed by European Accessibility Summit on 1-2 June 2021. Full details on both events can be found in the *Calendar of Events* section of this issue of *IFHOH Journal*.

HRF Talks

The organization of Swedish hard of hearing people, HRF, has recorded and published several helpful videos under the banner of *HRF Talks*, where experts talk about different subjects of interest to hard of hearing persons. The first one is presented by Gerhard Andersson and it discusses "Tinnitus - Is It Always a Problem?" The second one is presented by Jerker Rönnerberg and is entitled "We Hear with Our Ears but Listen with Our Brain". The third video is a presentation by Sarah Granberg on "A Sustainable Working Life". To find the English subtitles you click on the gear symbol and choose between English or Swedish subtitles. The videos are made available through a collaboration between HRF and EFHOH. Here is the link to all three *HRF Talks*: <https://www.efhoh.org/hrf-talks/>.

The European Disability Card and the Disability Rights Strategy

The new Disability Rights Strategy 2021-2030 was published by the European Commission in March 2021, after several years of intense advocacy by EFHOH and its members.

One of the key items that EFHOH and the EDF wanted to see included was the [European Disability Card](#) - and they succeeded! The Card will be one of the "Flagship Initiatives", that means it is one of the most important and visible actions of the new Disability Rights Strategy. And here's more good news: the European Commission promises to deliver the Card by the end of 2023 with a view to having it be recognized in all EU Member States. It will build on the experience of the ongoing EU Disability Card pilot project in eight Member States (Belgium, Cyprus, Estonia, Finland, Italy, Malta, Romania, Slovenia) and upon the European parking card for persons with disabilities.



It is still quite uncertain what such a Card will look like, what advantages it will cover, what legal form will be needed to establish it, and who will be eligible for it. All of this will now need to be determined.

Therefore, the EDF is planning several meetings and events to determine the position of persons with disabilities and further develop the vision of the Disability Card as it should

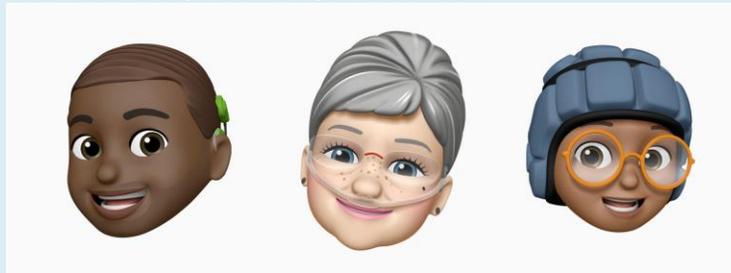
be. Bearing in mind that EU decision-making procedures take time, 2023 is not far off. The work has just begun! It is expected that the EDF will hold a consultative online workshop on the Disability Card on 16 September 2021, 10:00 - 12:00 CET.

EURO-CIU achieves a Cochlear Implant Memoji with Apple



At the last European Association of Cochlear Implant Users (EURO-CIU) Workshop in Barcelona 2018, members from all over Europe asked EURO-CIU to work on social media to have more visibility. On that point, its past Vice-president, Ervin Bonecz, explained that he had already started to lobby Apple for a Cochlear Implant memoji to raise awareness of our normally "invisible" disability.

On 20 May 2021, Apple announced that the new memoji's will be on additional features coming later this year to better represent users with **cochlear implants**, oxygen tubes, and those who wear a soft helmet for headwear.



Apple also announced new powerful software updates designed for people with disabilities. For example, it is launching a new service, called SignTime that enables customers to communicate with AppleCare and Retail Customer Care by using American Sign Language (ASL) in the US, British Sign Language (BSL) in the UK, or French Sign Language (LSF) in France, right in their web browsers. Also, in a significant update to the MFi hearing devices program, Apple is adding support for new bi-directional hearing aids. The microphones in these new hearing aids enable those who are deaf or hard of hearing to have hands-free phone and FaceTime conversations. The next-generation models from MFi partners will be available later this year.

Finally, Apple is also bringing support for recognizing audiograms — charts that show the results of a hearing test — to Headphone Accommodations. Users can quickly customize their audio with their latest hearing test results imported from a paper or PDF audiogram. Headphone Accommodations amplify soft sounds and adjust certain frequencies to suit a user's hearing.

Source: <https://www.apple.com/newsroom/2021/05/apple-previews-powerful-software-updates-designed-for-people-with-disabilities/>

<http://www.eurociu.eu>

<https://twitter.com/eurociu>

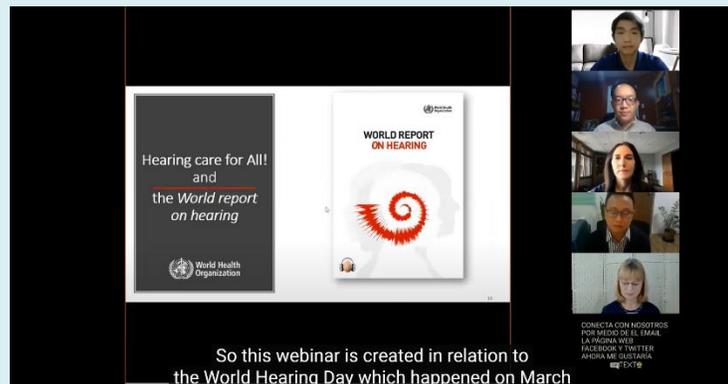


IFHOHYP UPDATE - By Bowen Tang, IFHOHYP President

Since the AGM in January, our Board, Committees and Members have been keeping busy in delivering high quality educational sessions, comics and stories, and planning upcoming virtual events.

World Hearing Day Webinar

On 6 March 2021, we had the pleasure of hosting a webinar "Remembering, Reimagining, Rebuilding: Life after Late Deafness" featuring speakers from U.S., U.K., and the Philippines to discuss the vital importance of peer support as an essential rehabilitation process for people with hearing loss in addition to receiving professional support from hearing health care professionals.



Virtual Social

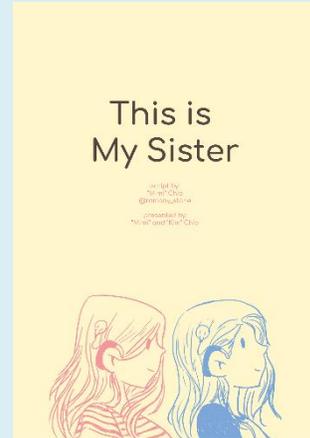


On 25 April, the strong desire to connect with one another yielded the opportunity for 50+ participants from more than 10 different countries getting together for our first online social meet-up. The excitement resulted in 3+ hours of non-stop chatting between participants.

In our commitment to ensure language inclusivity, Spanish captions were provided for Spanish-speaking participants in both the World Hearing Day webinar and the virtual social.

Comics and Graphic Stories

Our MIC committee is filled with spectacular talent as their team members produced entertaining and informative comics, stories featuring the lives of hard of hearing people. Be sure to follow us on Facebook (www.facebook.com/ifhohyp) and Instagram (@IFHOHYP) to check out future posts!



Awareness Raising & Capacity Building

Our Accessibility Committee is currently planning an educational session to share practical strategies for creating inclusion for hard of hearing people at museums.

We are also working with Hard of Hearing Group Philippines (HOHGP) and Africa Federation of Hard of Hearing (AFHOH) to empower their new officers through a leadership training program and pursuing scholarship opportunities.

Coming Soon

5 to 9 July - Virtual Study Session - *Advocating for Our Rights through Leadership*

After postponement of the study session in March to take place in Budapest, we are pleased to announce a virtual format for HOH people ages 18 to 35 to participate in this week-long intensive training session to build their leadership and advocacy skills. All information can be found in the application form (please read it carefully): <https://forms.gle/6ZeYnU8nsJ5cXbwe6>



12 to 14 August - Virtual Summer Camp
- *Hear the World: Share, Inspire & Interact*

Hosted by the Young Adults Network of Canadian Hard of Hearing Association, we invite HOH people ages 18 to 35 to a three-day interactive online event to Share, Inspire and Interact through both social and non-formal educational activities - aimed towards breaking down barriers by exchanging knowledge and experiences with their peers from coast to coast and internationally.

Visit www.yansummercamp.ca to register!

Calendar of Events



27 May 2021 - EDF Conference on Rail Accessibility

Location: **Online**

Link to info and registration: <https://www.edf-feph.org/events-slug/european-year-of-rail-2021-towards-independent-and-spontaneous-rail-travel-for-all-online-conference/>

This year is the "European Year of Rail". We highlight that equal and independent access to rail travel for persons with disabilities remains a goal rather than a reality. Ensuring equal access to rail is a EU obligation under the *UN Convention on Rights of Persons with Disabilities*, and under the EU Green Deal. International sign interpretation and live captioning will be provided.



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31 May 2021 - Cochlear Implants: Reframing our Advocacy Statement

Location: **Online**

Link to info and registration: https://zoom.us/webinar/register/WN_Bf5p_p-3TfC08lXeuVIM7Q

This session will be a discussion focusing on the issues that should be covered in the IFHOH policy paper on cochlear implants - from a consumer-based approach - covering topics of access, benefits, informed decision-making, and best practises. For more info, refer to page 6 of this issue, and consult the above link to info and registration.

* * * * *



1 - 2 June 2021 - European Accessibility Summit

Location: **Online**

Link to info and registration: [European Accessibility Summit 2021 \(https://www.edf-feph.org/european-accessibility-summit/\)](https://www.edf-feph.org/european-accessibility-summit/)

Organised by the European Disability Forum and sponsored by Microsoft, the Summit aims to raise awareness of the importance of accessible technology in furthering the employment of persons with disabilities in Europe. Keynotes, panel discussions and accessible, interactive breakouts will include leading voices from businesses, public sector and policy bodies and the disability community. This inaugural event will be part of a series of events related to the future of work and the role of digital technology. Against the backdrop of the new European Disability Rights Strategy, this is an opportunity for us to discuss and share specific business innovations, employees' stories, accessibility in online work, training, demonstrations of new technologies, and best practices in advancing the employment for persons with disabilities in Europe. The online conference will be fully accessible for persons with disabilities including International sign interpretation and live sub-titling in an accessible online environment.

* * * * *



Location: **Online**

Link to info and registration: [HLAA Virtual Convention 2021](#)

This three-day event includes a research symposium on *Hearing Care for All: Innovations in Extending the Reach of Hearing Care*, and robust workshops on advances in hearing aids, accessibility through mobile devices, hearing access in the workplace and more.

* * * * *

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



Location: **Haus Hainstein in Eisenach, Germany**

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

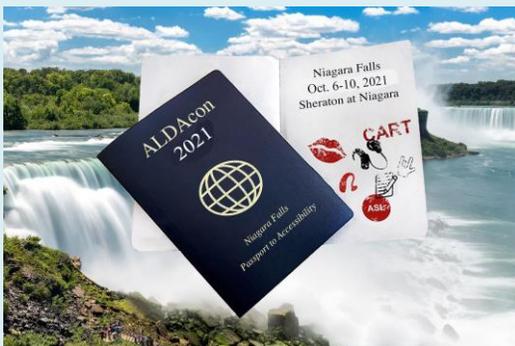
Contact: Barbara Adamus, board member

Email: post@churchear.org

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

* * * * *

6 - 10 October 2021 - ALDAcon Association of Late Deafened Adults (ALDA)



Location: **Niagara Falls, New York State, U.S.A.**

Information: <https://alda.org>

Contact: Kim Mettache, ALDAcon Chair

Email: aidakimmettache@gmail.com

This is an in-person conference. ALDA is monitoring possible restrictions related to COVID-19. Check ALDA website for registration information and updates: [Click here](#).

* * * * *



The International Federation on Ageing (IFA) will hold the [15th Global Conference on Ageing "Rights Matter"](#), both virtually and in-person in Niagara Falls, Canada on 9-12 November 2021. [Pre-conference master classes and summits](#) will be held on 9 November 2021. [Register now](#) The IFA 15th Global Conference will include presentations, debates and discussions on the action areas of the [Decade of Healthy Ageing](#). Find out more at www.ifa2021.ngo. You can also contact the Conference and Events Manager, Nathalia Wittingham, at NWittingham@ifa.ngo.

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8-11 June 2022 - FCEI International Conference

Location: **Bad Ischl, Austria**

Information:

<https://www.efhoh.org/ifhoh-world-congress-2020/>

Contact: fcei@bblinz.at

The FCEI (Family-Centered Early Intervention for Children who are Deaf or Hard of Hearing) has rescheduled the FCEI International conference date to 8-11 June 2022 in Bad Ischl, Austria. Online registration will begin in October 2021. Read more about the FCEI on its [website](#).

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

STUDY ON HOW PEOPLE CONTINUE SUCCESSFUL CAREERS AFTER HEARING LOSS



David Baldrige

How do people continue successful careers after hearing loss? In an interview-based study with 40 U.S.A. participants, David Baldrige (Oregon State University, USA; deafened person) and Mukta Kulkarni (Indian Institute of Management Bangalore) explore this question. Overall, they find that interviewees engaged in quests for meaning and big picture answers to 'who am I?' and 'am I still successful?' This quest often included redefining themselves - e.g. I am now both a person with a hearing disability (disability identity) and a successful professional (professional identity) - and career success (e.g., now I care about service to others as much as I care about

material success). Interviewees often also adopted new work roles where hearing disability was a key to success (e.g., becoming an advocate for people with hearing loss) and utilized new social networks to continue being successful (e.g., joining organizations like IFHOH, HLAA and ALDA). Results challenge ableism in the workplace by showing that disability can become a strength.

The full study was published in *Human Relations* (i.e., Baldrige D.C., Kulkarni M. *The shaping of sustainable careers post hearing loss: Toward greater understanding of adult onset disability, disability identity, and career transitions*. 2017; 70(10):1217-1236) and is available here: [10.1177/0018726716687388](https://doi.org/10.1177/0018726716687388).



Mukta Kulkarni

COVID-19 LINKED TO TINNITUS, HEARING LOSS AND VERTIGO



JamesKingsland

An article published in *Medical News Today* (1 April 2021) by Professor James Kingsland, National Institute for Health and Care Excellence in the United Kingdom, suggests that common symptoms of long-term COVID-19 include dizziness, tinnitus, and ear pain. Possible causes include infection of nerves, autoimmune damage, and blood clots. The findings are preliminary, as most of the reports of hearing and balance problems rely on patient questionnaires and medical records rather than diagnostic tests. [READ MORE.](#)

HARD OF HEARING ARTISTIC PHENOMENON

Time magazine (November 19, 2020) has recognized 14-year-old Tyler Gordon as an artistic phenomenon. He was born deaf and underwent an experimental surgery at age 5 that gave him some hearing. His biography says that he then learned to speak, leaving him with a stutter. His portrait of the Central Park Five fetched more than \$100,000 at auction. He won a 2020 Global Child Prodigy Award. He has started his own online platform for video tutorials called *Tongue Tye'd*, where he hopes he can show other young people how to use art to overcome their challenges as well. Tyler lives in San Jose, California, U.S.A.



Tyler Gordon with painting entitled "Can You Hear Us?" Photo credit: Douglas Zimmerman/SFGATE

"FUTURE HEARING JOURNEYS" REPORT



How will hearing care change in the next five to ten years? What implications will we see for people with hearing loss, hearing care professionals, educators, students, and the hearing care industry? And how can we get ready? The IDA Institute (not to be confused with the International Disability Alliance) has searched for answers to these questions, working to identify the trends and megatrends in hearing health care. Its *Future Hearing Journeys* report is based on an extensive insight-gathering process,

including interviews, focus groups, workshops, and a global survey. Here is a link to the report: https://idainstitute.com/fileadmin/user_upload/Future_Hearing_Journeys/Report_V1x/index.htm#/.

CIICA HOLDS ITS FIRST WEBINAR

On 5 May 2021, the Cochlear Implant International Community of Action (CIICA) held its first webinar and discussion on *The World Report on Hearing and CI Advocacy*. This first in a series of *CIICA LIVE* webinars was attended by 145 registrants from 30 countries. Presenters and participants shared information from the World Report on Hearing and its evidence for CI Advocacy. The webinar was also an opportunity to launch CIICA's new resources - summaries to help advocacy groups by providing the evidence in an accessible format (<https://ciicanet.org/resources/>).



CIICA LIVE Webinar presenters: Sue Archbold, Qais Khan, Leo De Raeve, Catherine Birman, Brian Lamb, Beatrice Cusmai, Paige Stringer and Eddie Mukaaya

SOUND PRINT

SoundPrint allows you to discover the quieter venues in your city. Using the app's internal decibel meter, you can measure the actual noise level of any venue, which is then submitted to a SoundPrint database that anyone can access to find out if a certain venue is quiet or loud. (SoundPrint measures the approximate decibel level and is not a replacement for a professional sound level measuring device.) A database for your city is created and, with each submission, is enriched and becomes more valuable. In addition, submitting SoundPrint measurements is an effective way to tell venue managers that you and others care about noise levels. Info: www.soundprint.co



OTONOMY ANNOUNCES RESULTS FOR OTO-825

On 14 May 2021, Otonomy, Inc., a biopharmaceutical company dedicated to the development of innovative therapeutics for neurotology, announced preclinical proof-of-concept results for OTO-825 presented at the American Society of Gene & Cell Therapy (ASGCT) Annual Meeting. OTO-825 is an AAV-mediated gene therapy targeting the gap junction beta-2 (GJB2) gene developed under the company's collaboration with Applied Genetic Technologies Corporation. These results demonstrate that a single administration of OTO-825 rescues hearing loss and cochlear damage in two preclinical models that represent a range of hearing loss severity caused by GJB2 deficiency.

Dr. Alan Foster, Chief Scientific Officer at Otonomy stated: "The treatment of GJB2 deficiency is an important unmet medical need since it is the most common genetic mutation causing congenital hearing loss with many patients experiencing significant impairment beginning at birth. These proof-of-concept results in two independent preclinical models are an important milestone for the program." (Source: <https://hearinghealthmatters.org/hearingnewswatch/2021/otonomy-gene-therapy-hearing-loss/>, Hearing Health Matters, 14 May 2021, Otonomy Presents Encouraging Preclinical Data for OTO-825 Gene Therapy Hearing Loss Treatment).

AUDIOBOOKS AS AUDITORY THERAPY TRAINING



Audiobooks can be a unique way to enjoy literature and to sharpen your hearing comprehension at the same time. Hearing is not just about recognizing sounds. We need to interpret them. Audiobooks can help us exercise those linguistic areas of your brain that are crucial for comprehension. You can also use them to practice listening to foreign accents or multiple voices while you're not under social pressure. Read more about this at: <https://www.healthyhearing.com/report/53200-Audiobooks-as-auditory-therapy-training>. (Source: *Healthy Hearing*, Temma Ehrenfeld, 10 May 2021).

DISABILITY, DISPLACEMENT AND CLIMATE CHANGE

In April 2021, the International Disability Alliance in collaboration with the UNHCR, the UN Refugee Agency's office for the Special Advisor on Climate Action, and the Internal Displacement Monitoring Center published a joint factsheet (link: <https://bit.ly/3t4dnka>) to highlight some key facts on the intersection of disability, displacement, and climate change. It notes, for example, that people with disabilities often face barriers accessing information and resources which limit their knowledge and capacity to adapt to climate change. For example, people with disabilities are more likely to be impacted by disasters, as disaster preparedness programs and early warning systems are often inaccessible - not provided in a manner that hard of hearing people can hear and understand.

Help us thank our sponsors by supporting them

This issue features Sivantos!



Our Mission

We invent the future of better hearing and understanding.

Our Vision

Build the leading hearing company by bringing cutting-edge innovation and customer care to all people suffering from hearing loss.

Our Guiding Principles

- Customers talk, we listen.
- Continuous improvement in all we do.
- We are honest and trustworthy with one another.
- We compete to win and create value for our stakeholders
- Quality is not an act — it's a habit.

IFHOH JOURNAL

The deadline for submissions for the next issue is August 15, 2021.
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*?
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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.



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