

# IFHOH JOURNAL

March 2021

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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 - 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 and IFHOH Special Advisor

Dear IFHOH friends,

It feels like it has already been a long time that our lives have been affected by the COVID-19 pandemic, and we are all wishing for the day our lives will return to normal. Sometimes it feels like it the way we lived our lives prior to the pandemic is a very distant memory. The outbreak of the coronavirus has presented challenges for everyone and although the development and distribution of vaccines presents hope that the outbreak will be contained soon, we are not there yet.

It was a difficult year for everyone, so we can forgive others and ourselves, for the most part, for times when tensions boiled over. At the same time, the stresses we are all coping with in varying ways are also a reason to be more compassionate.

Everyone is going through a tough time, so let us be more open and forgiving towards each other. We should demand better of ourselves. Let us spend more time focusing on the things that unite us as a community rather than on our differences. Ideally that also means less sniping at the people we share our life with, in person or online. It is a time for more constructive contributions. I am glad to report that IFHOH continues to contribute meaningfully to improving the lives of hard of hearing people around the world in so many ways, a few of which are mentioned in this issue of the IFHOH Journal.

It is impossible to anticipate everything that 2021 has in store for us, just as it was impossible to anticipate how 2020 was going to unfold. As tough as it has been, we made it through. I invite you to continue to be safety conscious, considerate of your neighbours and willing to pull together and make personal efforts for the greater good.

- Carole

## IFHOH President's Message



Dear Friends,

This year's World Hearing Day of 3 March will go down in history as a pivotal point for the hard of hearing community, the day in which the seminal report of WHO, the *World Report on Hearing*, was released. The Report is a response to the World Health Assembly Resolution 70.13, which was adopted in 2017, the first such resolution in almost three decades.

The World Report on Hearing is a comprehensive document about hearing health care and proposes a set of H.E.A.R.I.N.G interventions for implementation. Please see a summary in this issue for more information about the report.

The World Report on Hearing is important for our community as an advocacy tool to bring about improvements for the millions of persons in the world who have a hearing loss. The number of persons living with unaddressed hearing loss is unacceptable and we now have a powerful, evidence-based World Report to raise awareness about our issues and to bring about policy and programmatic changes.

The World Report will strengthen our capacity to advocate for hearing screening for persons of all ages, for affordable and quality hearing aids and cochlear implants, and for captioning for all, just to mention some of our issues.

Thank you to all of you for your activities, releases, and social messages on this year's World Hearing Day; please do share with us as have some of your colleagues in this issue. If you did not already see it, please go to the IFHOH website for our video message.

Please also download the *World Report* and note that we contributed, in particular, on the issue of captioning which is recognized in the Report as an important means of access for many of us.

Our work continues beyond the day of 3 March as do our efforts to raise awareness about hearing loss issues. One effort is to profile stories about our experiences. Further information about how to submit your story is included in this issue. Our stories are testaments to how hearing loss impacts on individuals and how challenges have been overcome or persist.

Another important day was celebrated at this time of the year, namely, Cochlear Implant Day of 25 February. This year the Cochlear Implant International Community of Action (CIICA) website was launched on that day. IFHOH is part of this advocacy network as a member of the steering committee. IFHOH also has its own advocacy project on cochlear implants, and, in this regard, we held a webinar in February on Cochlear Implant Experiences and Best Practise Tips. You can view the webinar at: https://www.youtube.com/watch?v=qurwU3rstZY.

You may have noticed that we have instituted an *IFHOH Bulletin* to regularly share news and information with you. These Bulletins are posted on our website (<u>www.ifhoh.org</u>) under the Information tab. The Bulletins are intended to share information in one place for your easy reference.

Among news shared in the IFHOH Bulletin is that Neeta Keshary of Nepal has been appointed Fellow for IFHOH to undertake a hearing healthcare access and communications project. She joins other Fellows, Brender Wanyana and Moses Serwadda, both from Uganda, who are undertaking an employment project. Please see this issue for the release about Neeta's appointment. I am honored to be able to work with our Fellows and look forward to our on-line meetings, held every two weeks.

Congratulations to Bowen Tang, who was re-elected as President of the International Federation of Hard of Hearing Young People (IFHOHYP) for a second term, and to other officers elected to their board. I attended part of their on-line annual meeting at the end of January. IFHOH is pleased to work closely with IFHOHYP on several projects, notably the survey about the coronavirus impact conducted recently.

Finally, for the latest update about the IFHOH World Congress, which was postponed from May 2020 due to the pandemic. We are still in a sea of uncertainty due to the coronavirus; with our European partner, SINOSZ, our hopes are pinned on rescheduling it next March 2022 and we will communicate any new plans as soon as they are finalized.

With warmest regards,

Ruth Warick IFHOH President president@ifhoh.org

## World Hearing Day 3 March 2021

#### The theme of the World Hearing Day 2021 was: Hearing care for ALL!

Screen. Rehabilitate. Communicate. Thanks to every organization and every person who organized an event or engaged in social messaging promoting and enhancing this year's World Hearing Day. Many of you communicated your message or shared your experiences or events on the IFHOH Facebook page at <u>www.facebook.com/groups/IFHOH</u>. You are invited to look at what has been shared online; you will find it all so very brilliant, awesome, and inspiring. And please do not hesitate to add your own events, experiences, and thoughts.

It is our hope that together we can learn from each other, and most of all, we will see our own selves reflected in our shared experiences and draw courage that will continue to inspire us all into taking responsibility and moving forward - taking concrete steps to improve the lives of hard of hearing people everywhere!





World Hearing Day 2021 marked the launch of the first ever World Report on Hearing, a groundbreaking document presenting a global call for action to address hearing loss and ear diseases across the life course. IFHOH President Ruth Warick posted a video message at www.ifhoh.org in celebration of World Hearing Day 2021. (This video recording also appears on the IFHOH Facebook page.) She describes the World Report on Hearing as "an important advocacy tool to improve policies and practices for hard of hearing people worldwide." The World Report on Hearing is available on the WHO website World report on hearing (who.int) or www.who.int/publications/i/item/worldreport-on-hearing. This seminal report responds to the World Health Assembly Resolution 70.13 adopted in 2017.

The World Report on Hearing summarizes the key public health interventions for the provision of hearing health care by using the acronym "H.E.A.R.I.N.G.": Hearing screening and intervention; Ear disease prevention and management; Access to technologies; Rehabilitation services; Improved communication; Noise reduction; and Greater community engagement (see page 202 of the Report). Integrated people-centred ear and hearing care, made available and accessible to all, will result in significant productivity outcomes not only for individuals, but also for entire communities, and nations. The Report contains recommendations for Ministries of Health:

- Include integrated people-centered ear and hearing care (IPC-EHC) in universal health coverage.
- Strengthen health systems to deliver IPC-EHC at all levels of care.
- Undertake awareness campaigns that address attitudes towards, and stigma related to, ear diseases and hearing loss.
- Determine targets, monitor national trends, and evaluate progress.
- Promote high-quality public health research on ear and hearing care (EHC).

The Report also provides recommendations for international organizations:

- Align with WHO's global targets for EHC and support their monitoring.
- Take steps to improve knowledge, attitudes, and practices with respect to EHC.
- Stimulate generation and dissemination of knowledge on EHC.
- Participate actively in global action for EHC.

Finally, the Report makes recommendations for stakeholders, including professional groups, civil society, and private sector entities:

- Support national governments and WHO in the provision and monitoring of EHC.
- Contribute to the generation of knowledge regarding public health aspects of ear diseases and hearing loss.
- Collaborate to ensure that all stakeholders can contribute to, and share a common vision of, EHC.
- Highlight the importance, need, and means for EHC, and advocate for its prioritization in government health agendas.



Participants in the first meeting of the World Hearing Forum (WHF) in December 2019 at the WHO headquarters in Geneva, Switzerland

## World Hearing Day in Uganda



By Moses Serwadda

The Uganda Federation of the Hard of Hearing UFHOH is a member of the International Federation of Hard of Hearing People (IFHOH) and of the World Hearing Forum.) On 3 March 2021, UFHOH joined the rest of the world to commemorate World Hearing Day, hosted at Bugema University, one of the prominent universities in Uganda, well known for its Health Sciences Program.



Organizing committee

Among the guests were prominent politicians, councilors, and local community leaders. University students attended in large numbers as they were interested in learning more about the *World Report on Hearing*. In addition, hard of hearing members travelled from various districts to share testimonials on their life experiences.

Presentations included:

- Moses Serwadda, a committee member of the Make Listening Safe initiative of the World Hearing Forum Working Group, presented on safe listening best practices.
- Nalubwama Mastulah, a member of the World Hearing Day working group, urged policy makers to take the *World Report on Hearing* seriously, because it presents useful information for the realization of universal health care.

• Hanifah Nalwoga, a member of UFHOH, spoke on communicating with hard of hearing persons and how to better support them.



A few of the participants

Politicians and local leaders pledged to promote and implement safe listening best practices and/or to further the *World Report on Hearing* recommendations.

The guest of honour was Ms. Guzu Beatrice, Executive Secretary of the National Council for Disability; she represented the State Minister for Disability and the Elderly. Ms. Beatrice congratulated organizers for promoting an understanding of issues related to hearing loss and hearing healthcare. She applauded the World Health Organization (WHO) for launching this first *World Report on Hearing* and pledged that the government will foster implementation of its recommendations. She said that the State Minister for Disability will aim to gazette this day on the ministerial calendar as well as work closely with UFHOH to raise awareness about hearing loss.



Ms. Guzu Beatrice

-

Three other activities also occurred related to World Hearing Day:

- Free hearing screening was provided.
- Meeting with Professor Patrick Manu, the Chancellor of Bugema University, who signed a statement of commitment and promised to create a network to offer free services regarding hearing healthcare as well as bursaries to hard of hearing students at the university. He urged UFHOH to continue with its safe listening campaigns since the university has primary, secondary and vocational schools which may need such vital information.
- A media briefing was held about the key messages of the World Report on Hearing and activities of World Hearing Day.

## World Hearing Day in Canada

The Canadian Hard of Hearing Association (CHHA) celebrated World Hearing Day with a national online webinar featuring Kris Martin, a professional NASCAR driver and motivational speaker who has had a hearing loss from birth. The international-level speakers were Dr. Ruth Warick, President of IFHOH, and Bowen Tang, President of IFHOHYP, who were both instrumental in organizing the event with Gordana Mosher of the CHHA National Office. The speakers list was rounded out by CHHA National President Marilyn Kingdon and CHHA National Executive Director Lee Pigeau.



Poster advertising the Canadian event

Dr. Warick stated that the *World Report on Hearing* promises to be a groundbreaking report that will lead to real action. There are two driving forces that provided guidance for the inception of the report. First, the report has been mandated by the WHO World Health Assembly. Second, it comes out of a collaboration with academics, consumers, professionals, manufacturers, and other stakeholders.

She noted that the report recognizes that hard of hearing people are an underserved population. Not only in developing countries, but in all countries, there is a high percentage of persons who could benefit from hearing aids but who do not have them. The percentage varies from 75% to 90% of people not getting the hearing aids they need.

Dr. Warick suggested that there exists an advocacy issue around hearing screening in that there are few screening programs for adults. "Using hearing screening as an example, we can take the WHO report and call upon our governments and policy makers to implement hearing screening across the life span. This is one example and there are others in the report including the need for the provision of hearing aids, cochlear implants, assistive technology, and captioning." "We have an opportunity to use our experience and to use the WHO report to press our governments for improvements to hearing health care and access. Let's seize this opportunity," she stated.

Bowen Tang, President of IFHOHYP, spoke about issues of concern to young people including the high cost of hearing aids and assistive technology. Kris Martin described his personal journey and overcoming barriers to become a race car driver. Lee Pigeau and Marilyn Kingdon outlined several initiatives being carried out by CHHA National to improve hearing accessibility and services for Canadians with hearing loss.



Top row, l. to r.: Gordana Mosher, Lee Pigeau, and Marilyn Kingdon Bottom row, l. to r.: Kris Martin, Bowen Tang, and Ruth Warick

Editor's Note: Dr. Warick contributed a background paper on captioning for the World Report on Hearing and summary points are included in the Report's subsection on Hearing Assistive Services.

## World Hearing Day in the U.S.A.



#### The Hearing Loss Association of

<u>America</u> (HLAA) is an IFHOH member organization. To celebrate World Hearing Day 2021, it joined forces with the <u>American Speech-Language-Hearing</u> <u>Association</u> (ASHA) to spotlight the domestic toll that untreated hearing loss takes on adults in the United

States—as well as the disparities in hearing health care in communities of colour. This has led to the online publication of the <u>ASHA-HLAA Member Digital Toolkit</u>, which may be of interest to the worldwide community of hard of hearing persons.

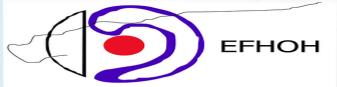
"We know that adults with hearing loss often wait years or even decades before seeking help," said HLAA Executive Director Barbara Kelley. "Many mistakenly feel they are getting by, but in reality they may be socially isolated, withdrawn or depressed, or experiencing declining health. We need to look at hearing loss as a whole health issue, and prioritize it accordingly. World Hearing Day gives us the opportunity to communicate that hearing loss is serious; effective treatments for it are available; and treatment makes a remarkable difference as adults live longer, and ideally more fulfilling, lives."



**Barbara Kelley** 

Recent U.S.-based research has documented disparities in hearing aid ownership across various racial, ethnic, and socioeconomic groups. A <u>research letter</u> published in *JAMA Internal Medicine* showed that while the proportion of older Americans who owned and used hearing aids increased from 15% in 2011 to 18.5% in 2018, fewer Black/African American individuals owned and used hearing aids across time than did White Americans. Researchers also found that ownership of hearing aids dropped across time among older adults living at less than 100% of the national poverty level (from 12.4% to 10.8%). Nicholas Reed, AuD, of the Johns Hopkins Bloomberg School of Public Health spoke more about this research on a <u>recent ASHA Voices podcast</u>. Past studies have also documented disparities, including a 2016 study in the <u>Journal of Aging and Health</u> found that among older Americans with hearing loss, non-Hispanic Black and Mexican American adults were 58% and 78% less likely, respectively, than were non-Hispanic White adults to report regular hearing aid use

On the bright side, U.S. Congressional Representatives Mike Thompson and David McKinley, co-chairs of the Congressional Hearing Health Caucus, submitted a resolution in the U.S. House of Representatives supporting World Hearing Day on March 3, 2021. The <u>resolution</u> expresses support for the goals and ideals of World Hearing Day.



European Federation of Hard of Hearing People





#### By Marcel Bobeldijk, EFHOH President

The EFHOH Board meets regularly using Zoom. EFHOH will be holding its Annual General Meeting (AGM) 2021 online on 19 May 2021. A lot of effort is going into making the technology work for this event.

With respect to the Live Text Access (LTA) project co-funded by the ERASMUS+ programme of the European Union, there is still some on-going work relevant to the need for harmonized training in the field of real-time intralingual subtitling. This has included a training programme, with new videos ready. Here is the link to the LTA project news page on the EFHOH website: <u>https://www.efhoh.org/lta-project-news/</u>.

EFHOH is also actively participating in efforts linked to the European Accessibility Act. This year the theme is linked to the European Year of the Railway. As a result, there will be some messages about access to information regarding train services, at the platform and over the public address systems.

Celebrations around **World Hearing Day** in Europe focused on an event in the European Union Parliament. I have posted videos of different portions of this event on IFHOH's Facebook page (<u>https://www.facebook.com/groups/ifhoh</u>).

Best wishes to all for continued health and safety.

## World Hearing Day in Germany

Parliamentary Evening to Improve Care for People with Severe to Profound Hearing Loss (On the occasion of World Day of Hearing 2021) (Editor's Note: adapted from Press Release issued by DSB, Berlin, 4 March 2021)



On World Hearing Day, members of the German Bundestag and state parliaments as well as representatives of various ministries engaged in the Parliamentary Evening organized by the German Hard of Hearing Association (DSB) to learn about the care needed for people with severe to profound hearing loss. The DSB called for better awareness of cochlear implants and more targeted education of health professionals to support people with severe hearing loss in referral pathways to cochlear implant treatment.

"When hearing aids no longer provide sufficient help for hearing impaired people and other therapy services are not available, this is accompanied by considerable health and social risks for those affected," explained Dr. Matthias Müller, President of the DSB. "The provision of high-quality cochlear implants allows hearing-impaired people to participate and enjoy a better quality of life. Unfortunately, the care path is far too often associated with almost insurmountable obstacles." Speakers make it clear that while cochlear implant provision is available in many places, those affected tend to have many questions and can struggle to make an informed decision.



Dr. Matthias Müller



Ursula Soffner

The realities of life for those affected were highlighted during the event with Ursula Soffner, Vice President of the DSB and herself a cochlear implant recipient. "I only learned that the option of a cochlear implant was available to me after years of searching in vain," said Soffner, "Whether it was my re-entry into professional life, my volunteer work in the DSB or even my membership in a choir - the CI has fundamentally improved my life and opened up things for me that seemed impossible for a long time."

Dr. Harald Seidler, head physician at the specialist ear, nose and throat clinic MEDICLIN Bosenberg in St. Wendel said, "People with severe hearing impairment are too rarely referred to a CI clinic." In addition, he said, the number of those who are profoundly deaf, yet do not have a cochlear implant, is increasing. To reverse this trend, all the professions involved in providing care - from ENT physicians in private practice and hearing care specialists to doctors and therapists in the clinics - must work hand in hand.

Organizers considered this first event a success: "We are pleased that our informative program was met with such lively interest," explained Dr. Matthias Müller, "We hope that this will help to establish the high standards of care that we already have at numerous centers in Germany on a nationwide basis." Driving this forward is not only the task of the professional groups involved, the CI clinics, and the patient associations: "Active support is also needed from political stakeholders and payers," said Müller.

Further information on the German Association for the Hard of Hearing e. V. (DSB) can be found at <u>www.schwerhoerigen-netz.de</u>. You can also contact Dr. Matthias Müller, President, and/or Renate Welter, Member of the Executive Committee, by email: <u>dsb@schwerhoerigen-netz.de</u>.



### Realities Facing Hard of Hearing Learners in Nepal and Uganda Insights from the IFHOH Report Team

"Inclusive education brings a sense of unity and respect amongst all learners irrespective of disabilities. Inclusive education requires support services for all students, leaving no one behind." - Brender Wanyana

"Inclusive education requires supports and reasonable accommodations in a nondiscrimination environment; unfortunately, we are not there yet for hard of hearing learners, requiring our advocacy for improvements." - *Patrick Gift Egessa* 

"This report is invaluable in sharing the challenges and realities being faced by hard of hearing learners in the education system of developing countries." - Jeevan Bhattarai

"This rights-based approach, carried out by hard of hearing persons about hard of hearing learners, provides valuable insights into the realities of inclusive education as well as guidelines for action for disability advocates, education sector stakeholders, researchers, donors, and policy makers." - *Karina Chupina* 

"This report will be definitely used to seek more inclusion for hard of hearing learners and to improve their educational experience in developing countries like Nepal and Uganda." - Neeta Keshary

"Being hard of hearing is an invisible disability, which is all too often unrecognized and unsupported as shown in this powerful Inclusive Education Report. Let it be a catalyst for change." – Ruth Warick

The report is available on the IFHOH website, here is a direct <u>link</u>. The webinar can be viewed at <u>IFHOH Workshop on Inclusive Education - November 30th 2020 - YouTube</u>.



Patrick Gift Egessa, Brender Wanyana, Ruth Warick, Neeta Keshary, Karina Chupina, and Jeevan Bhattarai

## **Rollout of COVID-19 Vaccines**

The World Organization and Unicef are currently working together to develop a new document entitled: *Disability Considerations in COVID-19 Vaccination*. IFHOH is among the international disability organizations currently being consulted on the draft document, as reported in the previous issue of *IFHOH Journal*.

The purpose of the joint WHO and Unicef document would be to provide recommended actions for different stakeholders to address barriers and promote equitable access to vaccination for persons with disabilities. It is expected to be in alignment with other WHO guidance on COVID-19 vaccination (the <u>WHO SAGE Roadmap For Prioritizing</u> <u>Uses Of COVID-19 Vaccines In The Context Of Limited Supply</u> and <u>Guidance on Developing</u> <u>a National Deployment and Vaccination Plan for COVID-19 Vaccines</u>, which already provide recommendations on the allocation and prioritization of vaccines globally and at national levels; also the WHO publication <u>Disability Considerations During the COVID-19 Outbreak</u>, which focuses more on containing the spread and mitigating the impact of the virus on people with disabilities.



On March 2, 2021, the International Disability Alliance (IDA) and the International Disability and Development Consortium (IDDC) launched a call to action requiring the inclusion of persons with disabilities in the worldwide COVID-19 vaccination rollout. This call focuses on UN Agencies and national governments to ensure persons with disabilities are recognised as a priority group and that vaccination plans are inclusive, equitable and accessible. Read more at: <u>Call to Action: Priority</u>, <u>Accessibility and Inclusion for Persons</u> with <u>Disabilities in COVID-19 Vaccination Rollout</u>. (Editor's Note: IFHOH is one of the founding members of the IDA, an international organization consisting of eight international organizations and five regional networks to advocate for the rights of persons with disabilities and sustainable development processes within the United Nations, upholding the highest standards of the Convention on the Rights of Persons with Disabilities.)</u>



### **IFHOH/IDA Fellow Appointed**

Impact of COVID-19 on Healthcare Access for Hard of Hearing Persons

The International Federation of Hard of Hearing people (IFHOH) and the International Disability Alliance (IDA) are pleased to announce that Neeta Keshary will be undertaking work about the impact of COVID-19 on healthcare access for hard of hearing persons in keeping with the UN Convention on the Rights of Persons with Disabilities and Sustainable Goal 3 "to ensure healthy lives and promote well-being for all at all ages."

This Fellowship Programme has a dual objective of providing support to the member organization's capacity to advance the rights of persons with disabilities while also building the capacities of individual disability activists through learning, mentorship, exposure to different policy, and project processes. This Fellowship will involve interviewing hard of hearing persons about the experiences during the pandemic, developing of a toolkit on good communication practises and access strategies, and hosting a webinar to share findings. The duration of the Fellowship is until July 16, 2021.

The Fellow, Ms. Keshary. Hard of hearing from birth, Neeta Keshary is the founding president of SHRUTI, a national association of hard of hearing and deafened persons in

Nepal and a member organization of the International Federation of Hard of Hearing People (IFHOH). She is a former Vice-President of the Asia Pacific Federation of the Hard of Hearing and Deafened. Ms. Keshary actively promotes accessibility, inclusive education, health care and the human rights of hard of hearing persons in Nepal. She is also involved in capacity building activities and in expanding the network of hard of hearing persons in her country. Ms. Keshary was a part of the research team which produced a report of its study on Inclusive Education Report: Realities Facing Hard of Hearing learners in Nepal and Uganda. She was also a member of the editorial team of a book, A Teacher's Manual for Teaching Students with Hearing Loss. She has been involved in conducting a research survey on the impact on hard of hearing of



COVID-19 in Nepal. Ms. Keshary has published many articles on issues facing hard of hearing persons in national newspapers as well as in the journals of different international organizations. She holds a master's degree in Sociology.



The International Federation of Hard of Hearing Young People (IFHOHYP) held its Annual General Meeting (AGM) 2020 on 30 - 31 January 2021 (yes, that is not a typo, its 2021 AGM will be held later this year). The event took place online and was supported by palantypists to ensure accessibility. IFHOH is pleased that it hit the highest number of participants ever in its history - up to 60 participants! The event included both the decision-making phase normally associated with an AGM and some fun time to allow for an opportunity to socialize.



On the first day, the different IFHOHYP committees were presented to the members - Accessibility, Fundraising, Member and Information, Policy and lastly, Study Session. IFHOHYP president Bowen Tang explained upcoming strategic planning. There was an opportunity to get to know the candidates better. The audience asked guestions related to their expectations for IFHOHYP's future.

On the second day, the AGM started with the official presentation of the Annual Report, the Financial Report, and the Auditor's Report, followed by the election of the officers of the Board. Congratulations to Bowen Tang, who was re-elected as President of IFHOHYP for a second term, and to other officers elected to their board.

## Health Worker with Hearing Loss during COVID-19

#### By Katharina Nitschke

(Editor's Note: When I read Katharina's story in a letter to IVSS Churchear members, I found it compelling and so I asked if I could share an edited version with IFHOH readers. She graciously agreed.)



Katharina taking a walk with her mother

I had been working since December at the hospital's emergency department, mainly with patients with COVID. Working there was difficult for me in our full "armor" with face masks, visors, and head bands, it was very difficult for me to understand. Most colleagues there were unknown to me, so I was unfamiliar with their way of speaking. Face masks made lip reading impossible. The visor pressed on the head band so tightly that I heard even less. Especially foreign doctors... I could hardly understand a single thing.

After every workday, I was completely exhausted. I asked to be transferred to another section, describing my situation. My supervisor understood, but it was not possible to make a change quickly, and unfortunately there was no one willing to change with me.

I considered asking my ear doctor to put me on a sick leave. Then I had a positive test for COVID. The Public Health Service sent me a four-page letter containing strict rules of behavior. I was forbidden to leave my house; I had to check my temperature twice every day.... I had to disinfect, disinfect, disinfect... I was coughing only. I also felt exhausted, exhausted. Through the first couple of days, I slept a lot. Eventually, I had a negative test. Now I am back at work, in my own ward where I know my colleagues and their way of speaking; even with a face mask can I understand them. And they know my hearing impairment. So things are better now.

A few months ago, a dear colleague told me: "Hard of hearing as you are you should really be exempted from wearing a face mask. It makes it impossible for you to lip read ..." I replied: "Well... I do have certain difficulties lip reading myself..." A doctor overhearing our conversation burst out laughing uncontrollably!

## **International Federation on Ageing Statement**



IFHOH is a signatory to a statement issued by the International Federation on Ageing linking hearing and healthy ageing together in a call for improved access to hearing care for older adults. It emphasizes five actions: 1. Increase awareness and tackle stigma 2. Synthesize and disseminate knowledge to change practice in the context of healthy ageing 3. Articulate economic advantages of hearing care and elevate hearing loss as a public health concern 4. Promote equity and access to hearing care 5. Apply evidence to guide actions. The statement is relevant given the new *World Report on Hearing* and the UN Decade of Healthy Ageing (2021-2030). Read the statement on IFHOH's website, www.ifhoh.org or Think-Tank-on-Hearing-in-Later-Life-Final-Statement-of-Intent-.pdf (ifa.ngo).

## Calendar of Events

25 March 2021 - WHO-IDDC Seminar Is Telehealth Accessible for People with Disability? 14:00-15:30 CET



#### Topic:

WHO-IDDC Seminar on Accessibility of Telehealth Services

#### Description:

The current COVID-19 pandemic has revealed that many people with disabilities experience difficulties accessing and using telehealth services. To address this, WHO and ITU have initiated the development of a global standard for accessibility of telehealth services. Join this seminar organized by WHO in collaboration with IDDC to discuss the challenges and outline concrete solutions that healthcare providers and manufacturers of telehealth platforms need to implement to make telehealth services accessible.

#### Agenda:

- Telehealth 101
- Telehealth users' perspectives
- WHO-ITU standard for accessibility of telehealth services
- Break out groups and feedback

\* Captioning will be provided for this seminar. Please let us know if you need any other reasonable accommodation to take part in the seminar.

Register here:

https://who.zoom.us/meeting/register/tJwqduCuqT4jHdE3xQIsz6sYLdPO1NCCNbbb

For more information: disability@who.int

#### 19 May 2021 - EFHOH Annual General Meeting 2021



European Federation of Hard of Hearing People

Location: Online Information: https://www.efhoh.org/ifhoh-world-congress-2020/

The European Federation of Hard of Hearing People (EFHOH) will hold its Annual General Meeting online on 19 May 2021. Please check the link above for updates,

#### 13 – 17 September 2021 – 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

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.



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

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#### March 2022 (TBC) - IFHOH World Congress



Location: Budapest, Hungary Information: www.ifhoh.org



#### 8-11 June 2022 - FCEI International Conference

Location: Bad Ischl, Austria Information: <u>https://www.efhoh.org/ifhoh-world-congress-2020/</u> 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 <u>website</u>.

#### 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

#### NEW COCHLEAR IMPLANT INTERNATIONAL NETWORK

The Cochlear Implant International Community for Advocacy (CIICA) is a newly established consumer/professional network. Its aim is to increase the number of children and adults globally who have access to cochlear implants and lifelong aftercare. Its website (<u>www.ciicanet.org</u>) was launched 25 February 2021 on International Cochlear Implant Day.

#### UNIVERSAL METRIC PROPOSED TO MEASURE HEARING LOSS

Dr. Frank Lin (Dept. of Otolaryngology, John Hopkins University) and Nicholas Reed (AuD) have expressed the viewpoint that while commonly used metrics (such as blood glucose level of 105 mg/dL, or blood pressure of 120/80) are familiar to both clinicians and the lay public, and are clinically meaningful, there are no such metrics that provide insight into an individual's hearing loss. This, in their opinion, has hindered the public's understanding of hearing loss, and has prevented nonaudiological health care providers from being able to understand the hearing status and communication needs of patients. They argue that "the medical and audiological communities need to converge on... the 4-frequency pure-tone average (PTA) of air conduction hearing thresholds in the speech frequencies (0.5, 1, 2, and 4 kHz)." (Source; JAMA Journal Otolaryngology Head & Neck Surgery, December 22, 2020) READ MORE.

#### GENETIC PATCH TO PREVENT HEREDITARY DEAFNESS

Persons with DFNA9 can hear well up to about forty years old, but then suddenly become deaf. The cells of the inner ear can no longer reverse the damage caused by a genetic defect in their DNA. Researchers at the Radboud University medical center in the Netherlands have developed a "genetic patch" for this type of hereditary deafness, with which they can eliminate the problems in the hearing cells. According to the researchers, further study in animals and humans is needed to bring the genetic patch to the clinic as a therapy. The specific DFNA9 mutation seems to originate from a common ancestor in the Southern Netherlands, somewhere at the end of the Middle Ages. It is now estimated to occur in about 1500 people in the (southern) Netherlands and Belgium. The research results have been published in the scientific journal <u>Molecular Therapy - Nucleic Acids</u> (Allele-specific antisense oligonucleotide therapy for dominantly inherited hearing impairment DFNA9). *Source: <u>Radboud University</u>* 

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## This issue features Resound!



ReSound constantly strives to develop better solutions that help people rediscover hearing so they can live rich, active and fulfilling lives.

With roots that reach all the way back to 1943, ReSound has pioneered the hearing aid industry and delivered a number of hearing industry firsts.

ReSound was the first to deliver 2.4GHz technology in hearing aids for direct connectivity and the world's first Made for iPhone® hearing aid with direct stereo sound streaming.

**ReSound is represented in more than 80 countries around the world.** 

Becoming an industry leader requires dedication, determination, and a desire to challenge the status quo. We strive to be experts in audiology and hearing solutions and combined with a strong focus in research & development, we empower you to hear more, do more and be more than you ever thought possible.

#### **IFHOH JOURNAL**

The deadline for submissions for the next issue is <u>May 15, 2021</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 of Directors**

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