



IFHOH JOURNAL

February 2017
v9

IFHOH President Ruth Warick
president@ifhoh.org

Journal Editor Carole Willans
journal@ifhoh.org

IFHOH Board

President, Ruth Warick (Canada)
Vice-President, Avi Blau (Israel)
General Secretary, Louise Carroll (New Zealand)
Treasurer, Heikki Niemi (Finland)
EFHOH Representative, Marcel Bobeldijk (The Netherlands)
Member at Large, Patrick Gift Egessa (Uganda)

In This Issue

From the Editor's Desk - by Carole Willans	3
IFHOH President's Message – by Ruth P. Warick	4
IFHOH Accessibility Conference – Call for Papers	6
Live Event Captioning / Speech-to-Text Interpreting – by Ruth P. Warick	9
A "Saint" for People with Hearing Loss – by Siegfried Karg	13
World Hearing Day	14
EFHOH News – by Marcel Bobeldijk	15
Swiss Bank Helps People with Hearing Loss – by Siegfried Karg	16
Indigenous People and Hearing Loss – by Corrine Walsh	18
Calendar of Events	21
News Bytes	24
IFHOH Sponsor – Amplifon	26
IFHOH Mission	27
IFHOH Board of Directors	28

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 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, 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 the views of IFHOH.

From the Editor's Desk



Carole Willans, Editor

Dear IFHOH friends,

I am sure that from time to time you find yourself rolling your eyes in exasperation at annoying things that happen to you because of hearing loss. Most are small things, but they do seem to pile up at the door! Then when you "open the door", all the exasperating things you experience fall on your head at once, and you want to cry, scream or vent some anger!

My pet peeve has to do with the people who have lived with me forever - my family. Even now, after all these years, they still wait until I leave the room in which I've just sat with them, and then ask me a question. I am in the kitchen or downstairs, there are walls between us, sometimes the television is blaring, and I AM SUPPOSED TO UNDERSTAND??? I was there with them moments before, so why did they wait until I left the room??? This is something that always has my eyes rolling in my head until I think I can see my brain....



Then there are things that I don't hear that get me in trouble, such as turning on a faucet in the kitchen and walking away "for a moment" - a VERY bad idea. Or leaving the dog outside to do her business on a very cold day, and then forgetting about her until one of those pesky family members lets me know that the

dog is barking VERY loudly! (And why exactly don't they let her in themselves, I do not know... sigh).



So what can we do? One of my favourite sayings is "*It's like water off a duck's back.*" To me, this means it's often best not to make a big fuss. Keep telling family members that you can't understand them from another room (or just don't answer at all, which actually works best - if it's important, they will ask again when you return). Laugh about your own mistakes, and learn from them (your floor and your dog will thank you!). So the message here is to find your path towards achieving resilience so that life's exasperating annoyances can better flow over you "*like water off a duck's back.*" You can send me email at journal@ifhoh.org.

IFHOH President's Message



Ruth P. Warick, IFHOH President

The *Call for Proposals* is out for the **International Accessibility Conference on Hearing Loops and Hearing Technology**, which is taking place October 6 and 7, 2017 in Berlin at the Best Western Plus - Hotel Steglitz International. This will be the fourth such conference. It was awarded by IFHOH to our German member, Deutscher Schwerhörigenbund e.V. (abbreviation: DSB). Please give thought to doing a presentation and mark on your calendar to attend. Aktion Mensch receives our sincere thanks for being a major sponsor for the conference. For the *Call for Proposals*, please see pages 6 to 8 in this issue of *IFHOH Journal*, then go to the IFHOH website to download www.ifhoh.org or you can also go to our Facebook page at www.facebook.com/groups/IFHOH.

We are gearing up for World Hearing Day on March 3. Materials promoting the 2017 theme of **Action for Hearing Loss; Make a Sound Investment** are available on the WHO website: <http://www.who.int/pbd/deafness/world-hearing-day/2017/en/>. Please share reports of your activities with us so that we can publicize these in an upcoming issue of *IFHOH Journal* and also share this information with the World Health Organization, a strong proponent of the Day. Avi Blau, IFHOH Vice-President, will represent us at a seminar about World Hearing Day in Geneva on March 3 and shortly after he will attend a joint meeting of WHO and the International Telecommunications Union (ITU) on the theme of *Make Listening Safe*. The purpose of this meeting is to discuss communications and protocols for safe listening devices and software.

In this issue you will find a write-up about the survey conducted for the joint IFHOH-World Federation of the Deaf captioning project for live events. The survey provides rich data that will help inform our advocacy work. In some respects, the findings

are not surprising. There is a wide divergence in methods used around the world and varying views about which is the best or preferred method.



Left: Catherine Seigler providing CART at a presentation – Right: Ahiya Kamara, former IFHOH VP, using CART

The majority of over 300 survey respondents reported a lack of captioning providers to meet demand with close to 90% finding it insufficient at times. This is a high number. As a friend of mine said to me on the weekend, there seems to be a feeling that either hearing aids or sign language interpreting meets the needs of the deaf and hard of hearing community; captioning is forgotten yet it is the primary means of communication access for many hard of hearing and deafened persons. We invite you to share your stories/opinions about captioning on the IFHOH Facebook page at www.facebook.com/groups/IFHOH or write to me directly at president@ifhoh.org.

In closing, you should know that your board is hard at work for you. Dr. Louise Carroll, General Secretary, new board member Patrick Gift Egessa from Uganda, and I will all be in Geneva next month during the meeting of the Committee on the Convention on the Rights of Persons with Disabilities; we will provide full reports. I will be attending a meeting of the project committee for the International Disability Alliance's three-year grant from the Department for International Development of the UK (DFID) during the first week of March in Athens. I look forward to learning about capacity-building opportunities within the project for IFHOH. Avi Blau, besides his WHO representations, will represent IFHOH at the EFHOH AGM in London in May. EFHOH President Marcel Bobeldijk continues to be actively involved in advocacy work and in advising us.

And, finally, Heikki Niemi, our Treasurer, is handling our finances and recently sent out membership notices. If you have not done so already, please pay your fees. Your membership in IFHOH is important to us. We need to be unified to seek the changes required at the international level that helps to make a difference in individual lives. Thank you for your support.

With best regards,
Ruth

Dr. Ruth Warick
President of IFHOH
president@ifhoh.org



International Accessibility Conference on Hearing Loops and Hearing Technology “Future Loops”

Friday, October 6 and Saturday, October 7, 2017

Call for Papers

It is with great pleasure that the International Federation of Hard of Hearing People (IFHOH) has awarded the hosting of the International Accessibility Conference on Hearing Loops and Hearing Technology, also known as *Future Loops*, to its German member, Deutscher Schwerhörigenbund e.V. (DSB). The conference will take place on Friday, October 6 and Saturday October 7, 2017, in the metropolis of Berlin, Germany.

Experts will assemble from numerous countries and bring their technical expertise, wide experience in designing of loops, and knowledge of accessibility for people with hearing loss. This event is an unparalleled opportunity to network, discuss progress and share ideas.

Submission Deadline:

The deadline to submit a proposal (including title and abstract) to the Call for Papers for the Conference is **Monday, 3rd of April 2017**.

- Speakers should be prepared to present on either October 6 or 7, 2017.
- Presentations will typically be 20 minutes in duration including 5 minutes for questions.
- The abstract will be posted on the DSB website.

The conference is designed for anyone interested in technology that provides accessibility for people with hearing loss: consumers, family and friends, audiologists, hearing aid providers, cochlear implant providers, captionists, sound engineers, architects, audio/visual designers and installers and manufacturers of hearing and assistive listening devices. As well, those involved in facilities covered by disability access laws or involved in accessibility committees are part of the intended audience.

Speakers are invited to contribute to the conference by submitting articles relevant to their profession or field of endeavour, sharing their expertise and experience in looping and

other future hearing technology, including significant advances, technical aspects and to how to advocate for them in communities throughout the world.

Topic Areas:

Three topics should run like a thread through the conference: *knowledge of technology*, *exchange of experiences* and *social dynamics*.

We encourage proposals that explore the latest technological advancements and standards related to hearing loops and hearing technology. The following themes are for inclusion but are not limited to:

- How can other countries benefit from your experience?
- How are standards enforced?
- How do we ensure hearing loops are installed properly?
- What do standards mean for the hearing aid user?
- Have hearing loop standards helped?
- How hearing aid users can become the advocates for hearing loops (AFILS) provision for performance and for other forms of hearing technology
- Experiences from around the world
- Education & awareness initiatives
- Looping and looking to the future

Keynote Speakers Confirmed Attending:

Horst Warncke

A social and technical innovator in the field of medical and hearing technology
Director Audiology Oticon GmbH, Hamburg, Germany

Juliette Sterkens

An audiologist in private practice and co-owner of Fox Valley Hearing Loop LLC in
Wisconsin, United States of America.

Peter Dieler

A counselor, coach and mediator for hearings issues working as an audio-therapist
at the HELIOS-Rehabilitation Center Bad Berleburg, Germany

Submission Guidelines:

All proposals must be submitted by attaching the completed Call for Papers Word document to an email. Any questions may be directed Dr.-Ing. Hannes Seidler at IFHOH-2017@hoer-umweltakustik.de.

Notification of acceptance will be by email by April 30, 2017.

Presentation Requirements:

By submitting a paper for the conference you will agree to provide the following:

- **Name and Contact** Information of all speakers involved.
- **Disclosure Statement** - disclose any and all real or potential conflict of interest.
- **Potential Conflicts** - Name any and all professional, financial, or personal affiliations which may cause the impression that bias or prejudice could affect the objectivity of material presented.
- **Presentation Title** - Name of the presentation as it will appear in our Exhibit and Programme Guide.
- **Short Description** of your proposed presentation to be used in the Exhibit and Programme Guide (Maximum 100 words).
- **Outline or overview** of your proposed presentation to be considered by the Conference Management Team in the selection process (Maximum 500 words), clearly stating objectives.

Speaker Responsibilities:

If accepted, speakers will be asked to sign a Presenter Agreement based on the following:

- That all participants in the presentation shall register for the Conference.
- Registration is free for all speakers only on the day of their scheduled presentation. If they wish to arrive early, or stay beyond the day of their presentation, then a discounted registration fee of 90 EUR will apply.
- To agree to present in the time slot and format assigned by the Conference Management Team.
- To grant permission to DSB to take photographs of you and to publish them at DSB discretion and in any format.
- Not to market specific products and services and refrain from overt selling.

Contact:

For more information and to register your interest in attending, please contact
Gudrun Brendel, Conference Manager: IFHOH-2017@schwerhoerigen-netz.de

Deutscher Schwerhoerigenbund e.V., please contact
Renate Welter, Vice President: dsb@schwerhoerigen-netz.de





Live Event Captioning / Speech-to-Text Interpreting

By Dr. Ruth P. Warick

Introduction

The International Federation of Hard of Hearing People (IFHOH) and the World Federation of the Deaf (WFD) are partners in a subtitling project to develop baseline information about different types of meeting/live event subtitling around the world and to identify key issues in providing this service. The ultimate goal of the project is to identify a list of acceptable speech-to-text parameters and providers for UN activities.

The provision of live-event speech-to-text/captioning involves the transmission of information on a visual display by a captionist/text provider. Live event refers to all sorts of live, in-person events such as meetings or conferences, the classroom, the workplace or ceremonies. The captions may be seen on a large screen, a separate large TV monitor, a smart tablet (such as iPad) or personal computer.

Survey

A global survey was conducted last May, consisting of 29 questions in sections focusing on services, administrative aspects and demographics. As of the end of May, 2016, 316 persons responded to the survey. The respondent profile was as follows:

Profile of disability
37% Hard of Hearing
34% Deaf
14% Other
10% Deafened
4% Hearing
1% Deaf/blind

Under "Other", several persons identified themselves as cochlear implant users; some individuals identified themselves as have dual disabilities or as orally deaf.

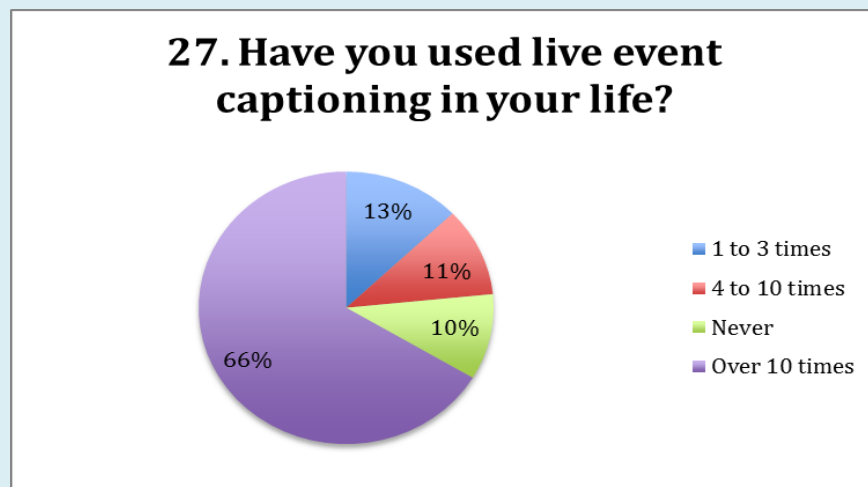
User profile
179 Hearing Aid Users
121 Assistive Device Users
116 Sign Language Users
94 Cochlear Implant Users
48 Oral Interpreting Users

Note: individuals were able to check off all of their applicable forms of access.

Country
 37% Europe
 30% United States
 14% Australia and New Zealand
 7% Canada
 7% Great Britain
 5% Asia
 3% Africa

Provision of Live-event Speech-to-Text/Captioning

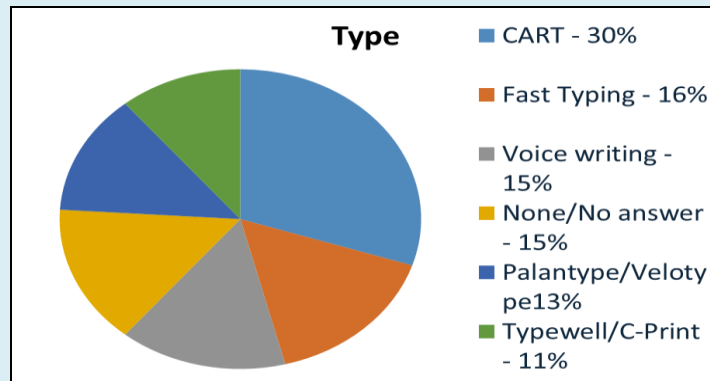
Most of the survey respondents reported that they had used live event captioning/speech-to-text with 77% reporting use 4 times or more. Ten per cent reported never having used it.



Some persons reported use of remote event captioning, but not to the same extent as in-person service provision:

32%	Over 10 times
18%	1 to 3 times
12%	4 to 10 times
37%	Never used

There are different methods of speech-to-text/captioning and the survey endeavored to learn which method was most in use by respondents. Responses showed that there is a wide divergence in methods used. Respondents who were familiar with CART (see definitions below) tended to rate this method above the other methods but this was also the case for those familiar with Palantypist and Velotype. Sometimes it was dependent on the skills of the service provider or on the nature of the event and the rate of speech of the speakers. The answer to the question about the best method is complicated by the availability of individuals trained in specific methods since variations exist as a country level. Further, a number of individuals responded that they lack any form of speech-to-text/captioning in their country.



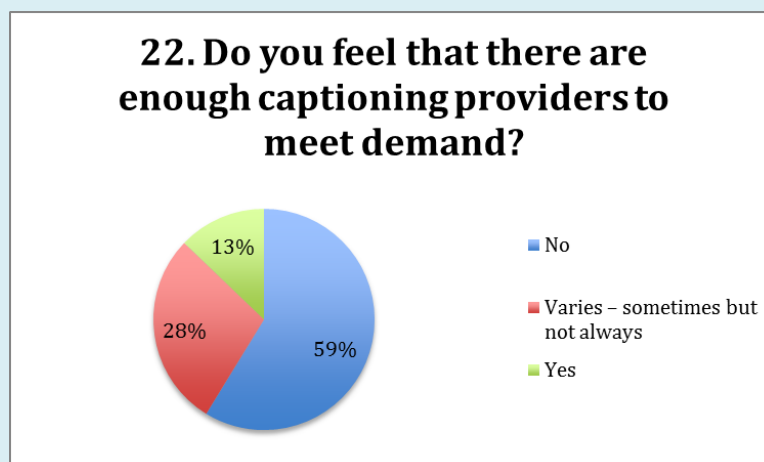
Note: CART refers to Communication Access Realtime Translation (uses a 'court' stenographic machine to produce text). Velotype and Palantype methods involve use of a special keyboard with shortcuts. Typewell and C-Print methods use a regular keyboard with hot keys to provide shortcuts.

The most common types of events for use of speech-to-text/captioning were conferences, meetings, on-line events such as webinars, theatre, post-secondary education and the workplace.

Respondents were asked how they view captions and responses were varied (more than one response was possible):

234 On a screen
 165 On own laptop computer
 164 On a monitor
 126 On a laptop by the provider
 78 Mobile phone
 68 Tablet

One of the most significant questions of the survey was the question: "Do you feel that there are enough captioning providers to meet demand?" Almost 60 percent stated that there was a lack of service providers; adding in those who sometimes could not have service, the total number who felt there were insufficient numbers of service providers at times was close to 90 percent.



Two-thirds of respondents had not experienced voice recognition speech-to-text/captioning or did not know what it was.

Administration

Regarding administrative details, 61% of respondents stated that they were responsible for booking a captionist and the other 39% reported that someone else had this responsibility. That could particularly be the case for a conference or a webinar.

Some respondents reported that there is funding in their country while other respondents reported no one paid for it in their country, particularly in countries of the global south.

Comments

The survey provided ample opportunity for respondents to write in comments. While it would be too lengthy to include them all, among some of them were:

I am Deaf AND I ALSO have attention deficit disorder. One reason I like CART rather than sign interpreter in some contexts is because CART is more "ADHD friendly" for me, if I zone out for a few seconds due to my ADD then the words stay on the screen so I can catch up.

Depending on the circumstances, the available sources and the audience, different methods may suit differently. In general, it is best to be able to select the particular method that suits best each time.

We are woefully short of captions in our public and private venues. Many captions we do have are too slow and not accurate enough. It is very difficult to convince hearing people that timely, accurate captions are necessary for people with hearing loss. Please help.

Technology is advancing so fast on many things. I hope that speech recognition can be achieved very soon to provide instant text anywhere.

I suggest not to jump into conclusions or be convinced too soon that the voice recognition technology is superior or most effective. Stay with the stenography tech for now while studying the effectiveness of voice writing.

In (country) there was never any live event caption in any conference or meeting, etc. because no one such government, education system, was willing to pay for this service. Only the closed caption company sometimes was willing to provide the live closed caption event for free.

Conclusion

The following are among the issues raised about speech-to-text/captioning. Many of these issues are not new but are confirmed by the survey.

- No common terms and understanding of them - individuals use different terms and there is a lack of a common understanding of the terms.
- Not available in some countries - there is a lack of availability of any service in some countries and even in developed countries almost 90% of respondents found insufficient providers.
- Lack of provision in the language of the country - software challenges of being available in different languages exist.
- Quality of service varies - qualitative differences arise regarding different methods.
- Funding challenges - funding for the service appeared good in some countries but totally lacking in other countries.
- Voice recognition potential unknown with some hoping that it will improve in the future.

A "Saint" for People with Hearing Loss

By Siegfried Karg, Winterthur, Switzerland

Margarethe von Witzleben (1853-1917) became hard of hearing at the age of 13. She organized the first worship service for hard of hearing and deafened people in Berlin in 1901. Eight years later she organized the first self-help group for people with hearing loss called "HEPHATA" in Berlin. The first association for hard of hearing and deafened people worldwide was founded in Berlin, Germany in 1909. February 1, 2017 is the 100th anniversary of her death.



Margarethe von Witzleben Gemeinschaftsstiftung

Today, the Hearing Loss Association of Germany (Deutscher Schwerhoerigenbund e.V.) walks in Margarethe's footsteps and will host the 4th IFHOH Accessibility Conference on Hearing Loops and Hearing Technology in Berlin, Germany, October 6-8, 2017. The theme is "Future Loops". More information is available at: <http://www.schwerhoerigen-netz.de/IFHOH-2017/english>; E-Mail: IFHOH-2017@schwerhoerigen-netz.de.

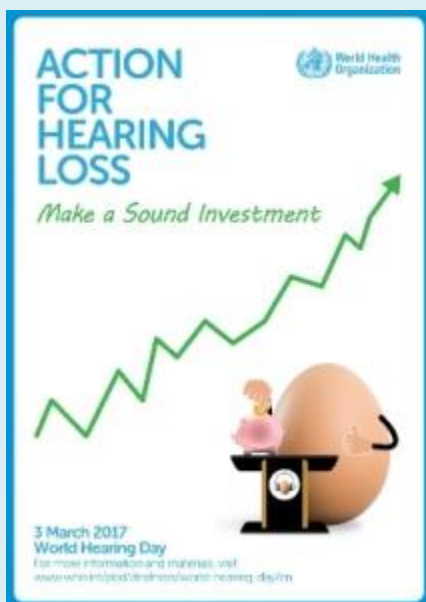
We honour Margarethe von Witzleben, this "saint" for people with hearing loss, for her outstanding service and we will continue to advocate for hard of hearing and deafened people until they receive the public acceptance they deserve. Hearing aids, cochlear implants, hearing loops, lip reading courses and aural rehabilitation can make life for them much more inclusive than at the time of Margarethe von Witzleben.



World Hearing Day

March 3

Action for Hearing Loss: Make a Sound Investment



The World Health Organization (WHO) has announced that the theme for World Hearing Day 2017 is "*Action for Hearing Loss: Make a Sound Investment*". The WHO intends to draw attention to the economic impact of hearing loss. "Unaddressed hearing loss poses a high cost for the economy globally and has a significant impact on the lives of those affected. Interventions to address hearing loss are available and are cost-effective."

Prevention, screening for early identification, rehabilitation through hearing devices, captioning and sign language education are among the strategies which can mitigate hearing loss and its consequences. World Hearing Day 2017 highlights actions which can be undertaken by decision-makers to address hearing loss."

IFHOH will be represented by Vice-President Avi Blau at the WHO launch for World Hearing Day on March 3, 2017.

Promotional materials provided by WHO

- ❖ [Brochure in English pdf, 4.95Mb](#)
- ❖ [Flierpdf, 1.16Mb](#)
- ❖ [Posters in Englishpdf, 912kb](#)
- ❖ [Banners in Englishpdf, 1.39Mb](#)

IFHOH President Dr. Ruth Warick and the IFHOH Board invite you to mark World Hearing Day on March 3 using the 2017 theme of *Action for Hearing Loss: Make a Sound Investment*. Any number of activities can be engaged in, from advocacy for service delivery as appropriate with your government through to hearing screening at a school or hospital, a public event to raise awareness, an art contest or a release to the media. Please take photos and report about your event by email to journal@ifhoh.org. Working collaboratively we can ensure that World Hearing Day is a successful awareness raising day and we look forward to seeing your activity reports emailed to us so we can share them through our *Journal*.

- Message from Dr. Louise Sinden-Carroll QSO, IFHOH General Secretary

EFHOH News



By Marcel Bobeldijk, EFHOH President

EFHOH has been busy responding to European Commission (EC) consultations, including its request for feedback on the *Smart Wearables - Reflection and Orientation Paper*. Some members have already experienced the benefits of smart technology used with hearing aids and cochlear implants. However Smart Wearables need to be safe, with no risk of noise induced hearing loss. So safety standards are important. Another key aspect is that hearing health care professionals must be part of the solution; they are responsible to help people to use Smart Wearables so that these function well in combination with hearing aids. Another aspect of wireless technology is potential interference. Small Bluetooth devices like hearing aids or cochlear implant processors have limited possibilities to protect themselves against interference. While further discussion is needed, EFHOH has recommended that rather than surrender all bandwidths to commercial interests, a small fraction of available Bluetooth bandwidth should be reserved and protected to ensure that hard of hearing citizens have the ability to function in society. Read EFHOH's feedback on Smart Wearables at <http://www.itu.int/en/ITU-T/jca/ahf/Pages/201701-docs.aspx> (refer to Document 285).

On a similar note, EFHOH has been lobbying jointly with the European Association of Hearing Aid Professionals (AEA) and the European Hearing Instrument Manufacturer Association (EHIMA) on growing concerns about radio spectrum sales across the European Union (EU). Read the joint letter on the potential interference in relation to deploying of LTE radio frequencies adjacent to the ISM band at <http://www.itu.int/en/ITU-T/jca/ahf/Pages/201701-docs.aspx> (refer to Document 284).

EFHOH has also been working on the *Audio Visual Media Services Directive* and the *European Accessibility Act* as part of EDF ICT Experts Working Group. I hope to provide updates soon on these important initiatives.

As announced in the previous issue of *IFHOH Journal*, the EFHOH AGM and Conference 2017 will be taking place in London (UK) May 5-7, 2017 under the theme "*Staying Connected, Informed and Empowered*". You can contact the event organisers at events@nadp.org.uk.

HOW TO CONTACT EFHOH

EFHOH	@efhoh
Marcel Bobeldijk	@marbob32
Lidia Best	@best_lidia

Swiss Bank Helps People with Hearing Loss

Mobile hearing loops in Credit Suisse Branch Offices in 2017

By Siegfried Karg

Credit Suisse, the second largest Swiss bank, has decided to put mobile induction hearing loops into all their Swiss branch offices in 2017. This is a major inclusive step to make banking easier for people with different disabilities. Although all their branch offices are already wheelchair accessible, people with the invisible disability of hearing loss had only a few branches with fixed induction hearing loops. This will now change.

The local Swiss Hard of Hearing Association in the region of Basel (Schwerhoerigenverein Nordwestschweiz), which celebrated its 100th anniversary in 2016, encouraged different companies, including banks in the area, to install mobile hearing loops at their ticket windows / counters. This will improve communication with people who wear hearing aids or cochlear implants.

The companies which agreed to this proposal were invited to a special meeting about induction loop technology last spring and were awarded with a "Golden Ear" donated by the Schwerhoerigenverein Nordwestschweiz.

The Credit Suisse branch office Basel was one of the participants in this project. Regula Tschopp, responsible for accessibility projects, was honored with the award. She had already been working to improve accessibility for people with hearing loss. The "Golden Ear" further helped her to spearhead her project of equipping all branch offices of Credit Suisse in Switzerland with a mobile hearing loop.



Presentation of the *Golden Ear* in Basel, Switzerland, May 31, 2016 (L.to r.: Rolf Auer (President of Schwerhoerigenverein Nordwestschweiz), Gabi Huschke (CEO), Regula Tschopp (Credit Suisse))

Photo credit: Marcel Richner

As Tschopp said: *"We at Credit Suisse want to demonstrate that we are an inclusive bank. This means we cannot exclude people with hearing loss - probably the largest group of people with disabilities. Because hearing loss is invisible, hard of hearing people are often forgotten. We want to change this. Communication with all our clients is very important to us."*



International hearing loop symbol

To use this technology, people have to switch their hearing aid / cochlear implant to the T-setting (via switch, push- button or remote control). Then the sound from the microphone of the teller will be transmitted wirelessly to their hearing systems. All disturbing background noise will be eliminated, thus considerably improving communication for people with hearing loss.



Credit Suisse will not be the first bank worldwide to provide hearing loops for their clientele. See Tim Archer and Mike Shaw, *Is Induction Loop Technology Old News?* in: *Canadian Audiologist* Vol. 3, Issue 5, 2016: *"Vancity (Vancouver City Savings Credit Union) was the first financial institution in Canada to install induction loops at the teller wickets in all of their branches. As a result of their 'teller loop' installations, Vancity received the 'Access & Inclusion Award 2013' which recognizes individuals and organizations who promote activities that enhance accessibility and inclusion of people with disabilities in all aspects of community life."*



Kudos to Credit Suisse for their inclusiveness. Let's hope that other banks and other companies where communication is important will follow their lead and adopt this excellent project for people with hearing loss.



Indigenous People and Hearing Loss



By Corinne Walsh

It comes as a shock to most people to learn that alarmingly high numbers of Indigenous people in Australia, in Canada, and in most nations around the globe are plagued by chronic and acute ear infections ('otitis media') and resultant hearing loss. According to very recent figures from the Menzies School of Health in Australia (2017), *nine out of ten* young Indigenous Australian children who live in remote communities have some form of ear disease. And *one in six* remote Indigenous Australian children have burst eardrums.

Having a mild to profound hearing impairment in both ears myself has given me a very keen interest in this topic. So much so, that I decided to undertake a PhD at the Australian National University at the beginning of 2016, which is seeing me use an anthropological (community-based) methodological approach to shed light on the little-appreciated Indigenous understandings, perspectives and experiences of ear and hearing issues.

Before I launch into a description of my PhD research, an overview of my own experiences with hearing impairment may be helpful. I have recently turned 30 years of age, and have had a mild to profound, binaural (both ears), sensorineural (nerve-related) hearing loss for virtually my whole life. Doctors believe my hearing was damaged when I had a severe case of the measles at the age of 2. However, my hearing loss was not picked up 'til I was almost 4 years of age. My family and kindergarten teachers were wondering why I was ignoring them when my name was being called, turning the TV up full volume, and holding peoples' faces with my hands when they spoke to me. I was doing this in order to read their lips and work out what they were saying. Mum and Dad were told that the age of 4 was quite late for a hearing loss to be diagnosed, and that - ideally - intervention should have occurred much earlier, before my speech and language development. So, I had a lot of catching up to do. I was fitted with hearing aids and my wonderful, dedicated parents read books to me every single night, and sat me in front of the mirror to learn to communicate. Audiologists, ear nose and throat specialists, speech therapists, support teachers and my family and friends all worked extremely hard to make sure I could participate in the hearing and speaking world. I also had to work very hard too. Without hearing aids, I can hear low-pitched sounds pretty well (e.g. an aeroplane flying overhead or deep music), speech sounds not that well, and high-pitched noises (e.g. a doorbell, a whistle or a phone ringing) barely at all. With hearing aids though - and with my skills reading lips and body language - I can essentially function like a person with 'good' hearing.



Torres Strait Islander Flag

While working in the Australian public service in Canberra a few years ago in an Indigenous employment program, I learnt how many Aboriginal and Torres Strait Islander people were not able to engage in work, education or in many aspects of social and cultural life due to ear and hearing problems.

I did a bit of investigating and realised there is little awareness of this issue (especially by policymakers and others making significant decisions about Aboriginal peoples' lives). I also was concerned that seemingly little was being done about it. This drove me to want to make a difference. I left the public service, enrolled myself in a Masters of Applied Anthropology and Community Development degree at the Australian National University (ANU), and secured a job as a researcher at the National Centre for Indigenous Studies, a cutting-edge research institution also

situated within the ANU, led by high profile lawyer and Indigenous rights advocate, Professor Mick Dodson AM.



At the end of 2015 I successfully completed my Masters, and shortly after enrolled in a PhD. If all goes to plan, my PhD will be finished at the beginning-middle of 2019. I have in fact heard of people taking 10 or more years to complete their thesis though... so who knows just when I may finish! I guess that's why they tell that you must choose a topic you are vehemently passionate about! ☺

Back to explaining more about my PhD - an anthropological analysis of Indigenous otitis media and hearing loss. *Otitis media* is the classic medical term for 'middle-ear infection'. Literally, otitis media means 'inflammation of the middle ear' in Latin. 'Ot' being *ear*, 'itis' being *inflammation* and 'media' being *middle*. Otitis media is more commonly known to us all as 'glue ear'. In the view of medical experts, it is a bacterial infection, thought to be the result of a common cold. Inflammation and fluid accumulation causes soundwaves to be unable to pass through the ear, and consequently the person will have difficulty hearing. The infection can come and go, meaning that quality of hearing can also fluctuate.

Recurrent or acute cases of otitis media are conventionally treated with ear drops and antibiotics. If no relief is obtained from this, then surgery is to be considered, where tubes are inserted into the ear to drain the infection. This is commonly known as 'grommets'. If the ear infection persists, then the eardrum can burst, and this results in permanent hearing loss. Once a person's hearing is damaged, assistive devices such as hearing aids are the recommended option.

Otitis media is quite a common childhood condition. According to the NSW Board of Studies, some 75% of all Australian children have had an episode of glue ear by the age of five, but most of these children recover without any damage to their hearing (1994). However, as mentioned in the opening paragraph of this article - amongst Indigenous Australians, especially young children, middle ear disease is extremely widespread, acute and chronic.

Otitis media and associated hearing loss affects many Indigenous cultures around the globe. For example, among First Nations, Inuit and Metis people of Canada, the prevalence of otitis media is 40 times that of their non-Indigenous counterparts (Bowd 2005).

But, the Aboriginal and Torres Strait Islander people of Australia have been found to have the highest rate of otitis media in the world. This has prompted the World Health Organisation to call it a public health crisis requiring urgent attention (Burns & Thomson 2013).

According to medical and public health literature, the high rates of Indigenous ear disease are due to pathogens or bacteria which come about from living in poverty and disadvantage; poor personal hygiene; overcrowded housing; swimming or bathing in polluted water; inadequate food and nutrition; exposure to cigarette smoke; and bottle-feeding as opposed to breastfeeding.

Undetected hearing loss can have devastating consequences for individuals, families and communities. For example, delayed speech and language development; misbehaviour and boredom at school; poor educational attendance and performance; social exclusion; low self-esteem; poor mental health; unemployment; violence and abuse; drug and alcohol use; criminal activity; incarceration and suicide and self-harm. A 2011 study by Vanderpoll and Howard found that an astonishing 94% of inmates in Northern Territory correctional facilities had a significant hearing loss.

Interventions such as vaccinations, antibiotics, ear drops, hand-washing and nose-blowing campaigns, hearing aid technologies and amplification systems in schools have all been directed at

Indigenous communities in the last few decades, in an attempt to address otitis media and resultant hearing loss. Yet, the rates still continue to escalate.

The focus has very much been on the identification, treatment and management of ear and hearing problems, with very little focus on prevention (Adams 2007). It is widely acknowledged in the literature that responses to date have been sporadic, short-term and unsuccessful. As these two quotes highlight:

- "two decades of research have not translated into sustained improvements in ear and hearing health outcomes for Aboriginal and Torres Strait Islander communities" (Queensland Health 2009)
- "governments' responses to the causes of Indigenous hearing loss have been intermittent and ineffective" (de Plevitz 2010).

There is a pressing need for a deeper and more holistic analysis of ear disease and hearing loss. While there is quite a robust literature out there on Indigenous otitis media, it is predominantly from a biomedical and public health angle. The voices of outside experts - such as medical researchers, health professionals and policymakers - are most prominent when it comes to defining the problem and formulating solutions. Medical narratives are certainly crucial inputs to Indigenous ear disease and hearing loss, but it is critical to ask: what other voices might be being left out, marginalised or silenced in this approach?

Very little is currently known about ear and hearing issues from the perspective of the Aboriginal people on the ground who have to live with it. There were some interviews done with Aboriginal parents in Western Australia in 2004 by researchers from the Telethon Institute in Perth (see Jeffries-Stokes et al), which seems to be one of the only qualitative studies done to date in Australia regarding Aboriginal views of otitis media. However, no in-depth ethnographic research on Indigenous ear and hearing health has been done, at least in Australia. It is clear to me that the Indigenous voice is noticeably absent in the framing of ear disease and hearing loss - and this is the gap I want to fill with my PhD research. In mid-February this year, I will be heading up to the Aboriginal community of Yarrabah (situated near Cairns in far north Queensland). I will base myself in the community for about 6 months talking to people and observing daily goings-on, in an attempt to understand how otitis media and hearing loss are viewed and dealt with at the very grassroots level. Indigenous people around Australia and the globe have age-old understandings of the body, health, illness and healing. These understandings can be significantly different from non-Indigenous conceptualisations, and even quite at odds with the biomedical paradigm (Eckermann et al 2010). It is imperative to pay attention to these Indigenous understandings surrounding the ear and the sense of hearing and health and the body on the whole. King, Smith and Gracey describe it perfectly - "Indigenous people have little success with, and in fact often will not engage in, treatment that does not value their ways of knowing—especially those pertaining to health and wellness" (2009:76).

In my thesis I will be analysing a range of perspectives and experiences surrounding OM and hearing impairment - from high-level policy to lived accounts of Indigenous people themselves. The essential aim is to grasp how approaches to ear and hearing 'problems' can better resonate with Indigenous beliefs, values, perceptions and circumstances. How can we find a common 'intercultural' (see Hinkson and Smith 2005) common ground between seemingly opposing views of the body, health, illness and disability, so that more effective intervention and prevention initiatives for otitis media may be designed?

Editor's Note: Corinne Walsh is a PhD scholar at the National Centre for Indigenous Studies at The Australian National University in Canberra, Australia. She has provided references to source materials for this article; please send an email to journal@ifhoh.org for the list of references.

Calendar of Events

May 5-7, 2017 - EFHOH / NADP AGM and Conference



Location: London, United Kingdom

Information: <http://www.efhoh.org/news>

Contact: events@nadp.org.uk

The theme is *Staying Connected, Informed and Empowered.*

★ ★ ★ ★ ★

May 25-27, 2017 - Canadian Hard of Hearing Association Conference

Location: Sidney, B.C. (near Victoria), Canada

Information: <http://www.chha.ca/conference/>

Contact: conference@chha.ca



Mary Winspear Centre – Conference Venue



★ ★ ★ ★ ★

June 18-22, 2017 - 12th ICBEN Congress on Noise as a Public Health Problem

Location: Zurich, Switzerland

Information: www.icben2017.org



★ ★ ★ ★ ★

October 6-8, 2017 – 4th IFHOH Accessibility Conference on Hearing Loops and Hearing Technology

Location: **Berlin, Germany**

Information:

Website: <http://www.schwerhoerigen-netz.de/IFHOH-2017/english>

FaceBook: [FB/EuropeanFederationOfHardOfHearingPeople/4th Hearing Loops](#)

Contact: Gudrun Brendel, Conference Manager, IFHOH-2017@schwerhoerigen-netz.de



This important conference is organised by the German association DSB in collaboration with IFHOH. See page 6 of this issue for information on the call for papers.

★ ★ ★ ★ ★

October 11-15, 2017 – ALDAcon 2017

Location: **Orlando, Florida, U.S.A.**

Information: www.alda.org

Call for Proposals: <http://www.alda.org/aldacon2017/CFP-Final-12-28-16.pdf>



October 12-14, 2017 - Coalition for Global Hearing Health



SAVE THE DATE:
**8th International Conference of the
Coalition for Global Hearing Health**
Working Toward Global Access to Care for Hearing Health
<http://cghh.usu.edu/>

**University of Miami; Coral Gables, Florida
12-14 October 2017**



★ ★ ★ ★ ★

**November 8 - 10, 2017 - World Federation of the Deaf
International Conference**

Location: Budapest Congress Center, Budapest, Hungary

Information: <https://wfdeaf.org/event/3rd-international-conference-world-federation-deaf/>

Contact: glob@congressline.hu

The main theme of the 3rd International Conference of the World Federation of the Deaf
is "FULL INCLUSION WITH SIGN LANGUAGE!"



News Bytes News Bytes

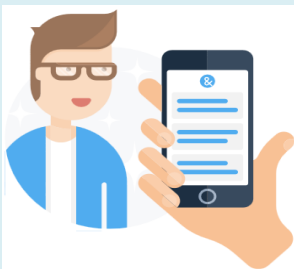
WHO CELEBRATES ITS ACHIEVEMENTS FOR 2016

On December 16, 2016, WHO Director-General Dr Chan indicated that the World Health Organization (WHO) was celebrating its achievements in 2016, despite global health challenges. "This year ends in uncertain times, for the world's political order, the fate of a damaged planet, the seemingly boundless human suffering experienced by civilians and health care staff in war zones, and the continuing failure of antibiotics that once gave medicine its 'miracle' cures." [READ THE NEWS RELEASE.](#)

WHO has chronicled some of the year's major health-related issues: [READ THE FULL REPORT.](#) For example, in 2016, WHO alerted the world to some alarming trends: the shortage of vaccines in Africa, the harm done to young people's health by gender and social inequalities, increasing deaths in Europe linked to alcohol consumption, **the scale of childhood hearing loss**, and the massive health consequences of polluted air. It is hoped that such alerts stimulate research and encourage action.



SMARTPHONES AND REAL-TIME CAPTIONS



An app called "Ava" was launched on iOS & Android in November, 2016. Its promoters say that "Ava turns smartphones in a room into smart microphones, allowing the deaf/hard-of-hearing person to read the entire conversation as real-time captions- including who said what." However they also emphasize that the app is not yet perfect and that there are still a lot of improvements the team is hoping to roll out soon.

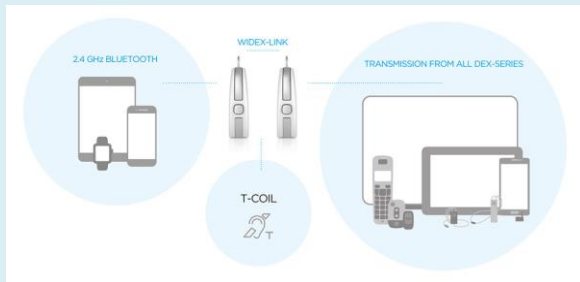
[READ MORE.](#)

FUN FACT: EAR WAX HAS SCIENTIFIC POTENTIAL!

A doctoral student at the Georgia Institute of Technology (U.S.) sees innovative potential in ear wax as a high-tech biomimetic adhesive surface and filter that can be used in a ventilation system for use in robotics and other kinds of machinery. The Society for Integrative and Comparative Biology explains in the *Science Daily* that the research is investigating earwax from pigs, sheep, rabbits and dogs. [READ MORE.](#)



WIDEX RELEASES HEARING AID MADE FOR iPhone



Widex released a new hearing aid, Widex Beyond™. The manufacturer promises "to meet consumers' expectations on sound quality, while also delivering on iPhone connectivity, telecoil support, and compatibility with all of Widex's proprietary wireless devices." [READ MORE.](#)

OVER-THE-COUNTER HEARING AIDS IN THE UNITED STATES

The U.S. Food and Drug Administration issued a guidance document in December explaining that it does not intend to enforce the requirement that individuals 18 and up receive a medical evaluation or sign a waiver prior to purchasing most hearing aids. This guidance is effective immediately. The FDA is also announcing its commitment to consider creating a category of over-the-counter (OTC) hearing aids that could "deliver new, innovative and lower-cost products to millions of consumers." This means that selling over-the-counter hearing aids will be allowed without requiring that consumers consult with a credentialed dispenser. [READ MORE.](#)



AMPLIFON WORLDWIDE: LATEST NEWS RELEASES



January 2017: Amplifon and Cochlear Italia have entered into an exclusive partnership agreement for the Italian market. [READ MORE.](#)

November 2016: "There is no class for noise": decibels are too high in Italian schools, and the noise can worsen report cards. [READ MORE.](#)

November 2016: Amplifon awarded prize for excellence in customer service for the second year in a row, in the category hearing centers. The survey was conducted by the German Institute for Quality and Finance in partnership with Goethe University in Frankfurt. [READ MORE.](#)

IFHOH JOURNAL

The deadline for submissions for the next issue is March 30, 2017.

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:
<https://www.ifhoh.org/journal>

FOLLOW IFHOH!

Website: www.ifhoh.org | Facebook: www.facebook.com/groups/IFHOH | Twitter: www.twitter.com/ifhoh

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



IFHOH Board

President, Ruth Warick (Canada)

Vice-President, Avi Blau (Israel)

General Secretary, Louise Carroll (New Zealand)

Treasurer, Heikki Niemi (Finland)

EFHOH Representative, Marcel Bobeldijk (The Netherlands)

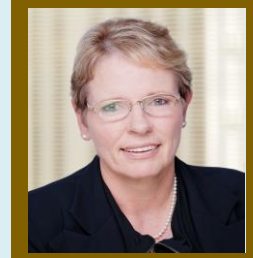
Member at Large, Patrick Gift Egessa (Uganda)



Ruth Warick



Avi Blau



Louise Carroll



Heikki Niemi



Marcel Bobeldijk



Patrick Gift Egessa