

Edited by Marcel Bobeldijk, president of EFHOH and Niels-Henrik M. Hansen.

Deadline for the next newsletter is September 10./2017.

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JULY 2017



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# EFHOH President letter

Dear Members,

At the European Federation of Hard of Hearing People (EFHOH) we are pleased with the approval of the WHO Motion at World Health Assembly on 30 May 2017, which raise the stakes in delivering national policy actions related to hearing loss prevention, treatment and rehabilitation. We are very happy to see the need for quality of hearing aids, cochlear implants and most of all quality of hearing care delivered by trained professionals as the prerequisite to reaching the best outcomes for the individuals has been clearly stated as part of the outcomes. EFHOH, together with our partners EHIMA and AEA look forward to supporting the implementation of the Resolution in Europe with our expertise and knowledge.

As a triangle = cooperation between EFHOH-AEA-EHIMA, we agreed a joint policy about our co-operation providing solid foundations for future. Soren Hougaard is retiring this summer and he will be missed by all of us.

It was great to meet most of the EFHOH members in London at EFHOH's AGM 2017. We would like to thank the members and the board of NADP for their great job as host. Also, we want to say thank you to all the speakers for their insightful presentations and thanks to all the sponsors who supported this event.

One of the most important result of our AGM in London was the EFHOH London 2017 Declaration. The declaration is based on the motion of the our member from Norway HLF with the support of the other EFHOH members from the Nordic countries.

At the AGM, we thanked Ritva Liisa Schädling for her great work as the interim treasurer and we welcomed our new treasurer Darja Pajk from Slovenia.

Lidia Best our vice president gave a presentation with preliminary results of EFHOH deafened survey 2017. We are planning to publish our deafened report after the summertime. At this moment, we are working on the EFHOH reimbursement report 2017, which will support the objectives of transparency and support for lobbying efforts. The cooperation in gathering the information by EFHOH and AEA members is very important for the success of this exercise. For EFHOH members who missed the original deadline, please send your responses or contact our office for the questionnaire.

The EFHOH AGM 2018 will be held in Slovenia and this will be organised together with the IFHOH BGM. Also in 2018, the host organisation will organise a conference day for our members and for the professionals and other people who are interested. You will find more information about the 2018 event in the EFHOH newsletter and in future EFHOH newsletters.



In the weekend after our AGM in London, Aida and I participated in the EDF AGA 2017 in Madrid, Spain. In this newsletter, you will find an article about this event. As a result of EFHOH active engagement, I was re-elected to the EDF Board of Directors.

Our board member Juha represented us at the Euro-CIU Symposium 2017 in Helsinki, he shares his experience with us in this Newsletter.

As you may know, on 6 and 7 October 2017 is IFHOH's 4th International Accessibility Conference on Hearing Loops and Hearing Technology in Berlin, Germany. In this EFHOH newsletter, you can find more information and the registration form. The registration form is also available on our EFHOH website.

#### Follow Us

It would be great if you follow us via social media on Facebook and Twitter. Our addresses are:

EFHOH	@efhoh
Marcel Bobeldijk	@marbob32
Lidia Best	@best_lidia
EDF	@Myedf

#### Summer Holiday

Dear members and EFHOH newsletter readers, we as the EFHOH board hope that you and your family have a great summer and that you will have a nice and sunny holiday.

Warm regards,

Marcel Bobeldijk







## EFHOH Annual General Meeting and Conference 2017

The 2017 Annual General Meeting and Conference of the European Federation of Hard of Hearing People (EFHOH) was held on May 5th-7th 2017 in London, United Kingdom. The theme of the conference on Saturday, May 6th was "Staying Connected, Informed and Empowered". The event was held at the Friend's House on Euston Road and was organized by The National Association of Deafened People (NADP).

28 delegates and observers from 12 European countries gathered on Friday, May 5th for the EFHOH AGM. Darja Pajk of Slovenia was elected as the new treasurer for EFHOH. EFHOH delegates also approved an important motion brought forward by a General Member from Norway that calls on the European Commission and European Parliament to put hearing loss on the political agenda and to incorporate hearing loss in population surveys in Europe. This document known as the London Declaration 2017 is available on the EFHOH website: <https://www.efhoh.org/resources> (read it on the next page).

Saturday's conference featured keynote speakers, including Dr. Laszlo Lovaszy (UN CRPD Committee and EU Parliament Advisor), Andrea Saks (Chairman of the ITU JCA-AHF), Søren Hougaard (Secretary General of the European Hearing Instrument Manufacturers Association), Mark Laureyns (President of the European Association of Hearing Care Professionals), Gareth Ford-Williams (Head of Accessibility, BBC Design and Engineering), David Bradshaw (Digital TV Group) and Sarah Herlinger (Senior Manager for Global Accessibility Policy and Initiatives at Apple).

There was well over 100 attendees at the conference and both days were made accessible with communication support including loop systems, lipspeakers and Speech to Text (STTR).

## LONDON DECLARATION 2017



### ***Hearing loss on a political agenda and in population surveys in Europe***

At the AGM 2017 in London, European Federation of Hard of Hearing People (EFHOH) delegates approved a motion brought forward by a General Member from Norway. The declaration reads as follows:

#### **EFHOH asks the European Commission and European Parliament to put hearing loss on the political agenda and to incorporate hearing loss in population surveys in Europe.**

In Europe, an estimated 52 million people have a hearing loss or deafness that significantly affects their daily life, leading to social isolation and loss of employment and education opportunities. Of this group, some require extensive rehabilitation while others require adaptation measures, hearing aids and awareness to master their daily life. Hard of hearing people are a diverse and growing group, as an increasing number of people are affected by hearing loss.

Treatment for hearing loss in Europe is fragmented and follow-up for patients is often haphazard. There is also a lack of research on hearing loss and hearing-related issues in Europe. Demographic variables have shifted and since the 90's the population has increasingly been exposed to both occupational and recreational noise sources. The World Health Organisation (WHO) has identified hearing loss as one of the most frequent permanent disabilities in the Western world and has shown that hearing loss is increasing in all age groups<sup>1</sup>.

An incorporation of hearing loss in national and European population surveys and public health statistics will give the public sector a better understanding of hearing loss and provide a basis for developing better health services. It is important that decisions and actions are evaluated with sufficient knowledge and competence. An awareness of hearing loss can be easier to explain, and in turn counteract, accidental falls, isolation, mental illness and incapacity for work. Research also shows that elderly people are often diagnosed with dementia when hearing loss is the real issue<sup>2</sup>, and that untreated hearing loss increases the risk of dementia.

Hearing loss is also a hidden factor behind other ailments, such as neck and back issues. An incorporation of hearing loss in population surveys will provide an understanding for the best targeted and most effective form of prevention.

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<sup>1</sup> Hearing loss due to recreational exposure to loud sounds. A review. World Health Organization 2015. ISBN 978 92 4 150851 3

<sup>2</sup> Hearing loss in the elderly, doktoravhandling av Jorunn Solheim, Universitetet i Oslo 2011



## “Hearing loss on a **political agenda** and in population surveys in **Europe**”

On 5th May 2017, the delegates gathered for the EFHOH AGM in London and adopted a new resolution in support of the motion from our Norwegian members. This resolution is now called the ‘London Declaration 2017’.

The London Declaration sends a very powerful message to the European Commission and the European Parliament. It states as follows:

EFHOH encourages the European Commission and European Parliament to:

- Develop and adopt a strategy on hearing loss issues that focuses on equality, prevention and rehabilitation to make everyday life easier for hard of hearing-people and ensure that the strategy is led by the experts who are working in the field and who are in direct consultation with hard of hearing people.
- In addition to the strategy, develop a plan to increase awareness of hearing loss in geriatric care professionals

- Conduct research on hearing loss (including research on prevention and rehabilitation) and produce relevant statistics to improve wellbeing and improved outlook for hard of hearing people

- Participate in a joint European conference on hearing loss that highlights good practices from the European countries on how to improve everyday life for hard of hearing people through joint efforts and collaboration.

The EFHOH Board is now working hard to put this Declaration into practice and we are strongly encouraged by the developments of the new Resolution agreed at the 72 World Health Assembly, in Geneva on 30 May 2017.

### “Resolution on Prevention of Deafness and Hearing Loss”,

The main recommendations:

- (1) to integrate strategies for ear and hearing care within the framework of their primary health care systems,

under the umbrella of universal health coverage, by such means as raising awareness at all levels and building political commitment and intersectoral collaboration;

(2) to collect high-quality population-based data on ear diseases and hearing loss in order to develop evidence-based strategies and policies;

(3) to establish suitable training programmes for development of human resources in the field of ear and hearing care;

(4) to ensure the highest possible coverage of vaccination against rubella, measles, mumps and meningitis, in line with the immunization targets of the global vaccine action plan 2011–2020, and in accordance with national priorities;

(5) to develop, implement and monitor screening programmes for early identification of ear diseases such as chronic suppurative otitis media and hearing loss in high-risk populations, including infants, young children, older adults and people exposed to noise in occupational and recreational settings;

(6) to improve access to affordable, cost-effective, high-quality, assistive hearing technologies and products, including hearing aids, cochlear implants and other assistive devices, as part of universal health coverage, taking into account the delivery capacity of

health care systems in an equitable and sustainable manner;

(7) to develop and implement regulations for control of noise in occupational settings, at entertainment venues and through personal audio systems, as well as for control of ototoxic medicines;

(8) to improve access to means of communication through promoting alternative methods of communication, such as sign language and captioning;

(9) to work towards the attainment of Sustainable Development Goal 3 (Ensure healthy lives and promote well-being for all at all ages) and Goal 4 (Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all) in the 2030 Agenda for Sustainable Development, with special reference to people with hearing loss;

We are encouraged by both resolutions and activities at all levels of advocacy. The issues of hearing loss, rehabilitation and accessibility as well as awareness rising have been fully addressed. We are now entering next stage, implementation and monitoring. Your active participation will be crucial to develop national strategies with full consultation with hard of hearing people and the advocates.

EFHOH will continue its support and monitoring, please get in touch with us if you need further clarification on the matters related to the European strategy.

Lidia Best



# European Triangle cooperation

## History

On May 27 – 29, 1999, the European Hearing Instrument Manufacturers Association (EHIMA) hosted a conference in Brussels called “World of Hearing”. Ambitions were high, there was an impressive list of scientific speakers, including Adrian Davis, Lucien Antheunis and Manuela Joore, and the whole world was invited to attend. But almost nobody came and the event was EHIMA’s biggest and most expensive failure ever. But one good thing did come out of this, namely two important lessons:

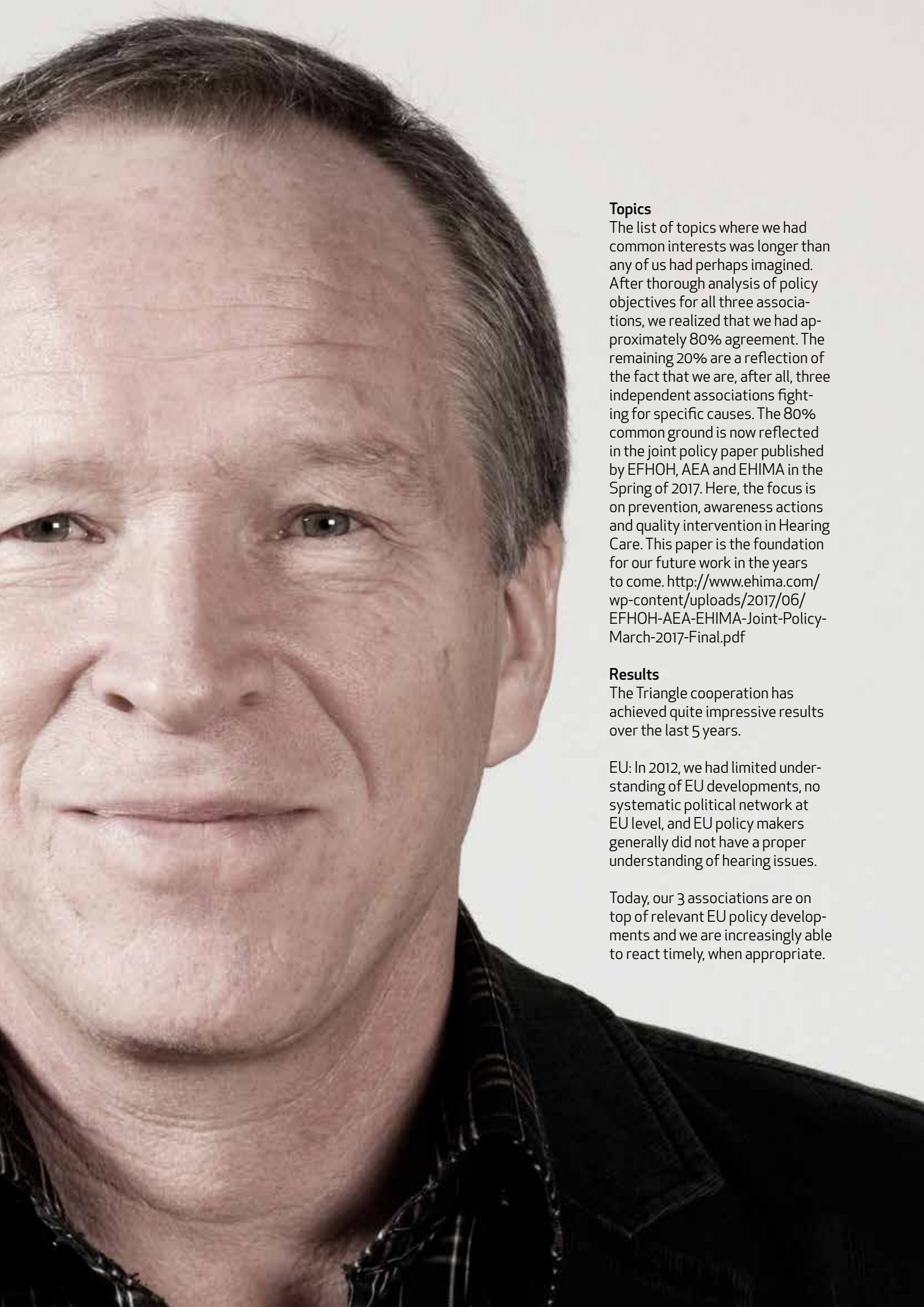
1. We cannot ask “the world” to come to us. We must communicate out to the world.
2. We cannot spread our good messages alone. We need to cooperate with the organizations for the hard-of-hearing and the hearing aid professionals.

This led to the formation of the non-commercial association Hear-it which included exactly the organizations for the hard of hearing (IFHOH, later on also EFHOH) and the professionals organized in AEA. The [www.hear-it.org](http://www.hear-it.org) web site was established in English, German, French and Spanish. Later on also Portuguese/Brazilian and Chinese. Today, this web site is 16 years old and still growing, with an annual number of individual visitors approaching 5 million. A true success story in the field of hearing care – and the idea of “triangle cooperation” between hard-of-hearing people, the professionals who serve them and the hearing aid manufacturers was born.

In June 2012, during the IFHOH congress in Bergen, Norway, the triangle idea took on a new dimension. Representatives from EFHOH, AEA and EHIMA met to discuss closer cooperation and it was quickly apparent that our policies and objectives were very much overlapping. We agreed on a number of joint activities and on a close, open-minded communication amongst ourselves.







### **Topics**

The list of topics where we had common interests was longer than any of us had perhaps imagined. After thorough analysis of policy objectives for all three associations, we realized that we had approximately 80% agreement. The remaining 20% are a reflection of the fact that we are, after all, three independent associations fighting for specific causes. The 80% common ground is now reflected in the joint policy paper published by EFHOH, AEA and EHIMA in the Spring of 2017. Here, the focus is on prevention, awareness actions and quality intervention in Hearing Care. This paper is the foundation for our future work in the years to come. <http://www.ehima.com/wp-content/uploads/2017/06/EFHOH-AEA-EHIMA-Joint-Policy-March-2017-Final.pdf>

### **Results**

The Triangle cooperation has achieved quite impressive results over the last 5 years.

EU: In 2012, we had limited understanding of EU developments, no systematic political network at EU level, and EU policy makers generally did not have a proper understanding of hearing issues.

Today, our 3 associations are on top of relevant EU policy developments and we are increasingly able to react timely, when appropriate.



We have built long-term constructive relationships with a number of decision-makers in Brussels, most of whom now understand our objectives and the current challenges in the area of hearing loss.

WHO: being able to participate in WHO stakeholder meetings with coordinated agendas has meant a tremendous improvement of WHO's understanding of hearing loss and its challenges. Our 3 associations are, today, among WHO's reliable stakeholders and WHO has – in turn – participated in our EU debate events on March 1st. This year's World Hearing Day slogan, "Action for hearing loss: make a sound investment" marked a high point in our joint cooperation, and the World Hearing Day is gaining momentum all over the world, heavily backed by our Triangle. We also pushed strongly for the World Health Assembly to approve the new resolution on hearing loss. To our delight, this was approved on May 30, 2017.

Raising awareness: Our 3 associations have mutually helped each other raising awareness among policy makers, professionals and hard-of-hearing people. We have actively participated in each other's annual congresses, symposiums and conferences, helping to spread important information to as many as possible.

When we fight globally for interference-free spectrum for our hearing aids and assistive listening devices, we now do this together. This has meant that e.g. the EU commission and the ITU have listened to our wishes & warnings.

### Outlook

"United we stand, divided we fall" is a good old saying which is also very relevant for our associations. Alone, there is little we can do to catch public attention – and that of policy makers – but together, we are much stronger than

the three of us individually. Furthermore, we can benefit from each other's network: e.g. EFHOH has a very good cooperation with the European Disability Forum (EDF). This relationship can now benefit also the AEA and EHIMA.

It is encouraging to note how hearing loss and hearing care are now included in discussions on general healthcare, both at EU and WHO level. For too long, hearing care was seen as a kind of "stepchild" dangling somewhere outside the realm of overall health policies. It is my sincere hope that professional hearing care will, in the future, be seen as a totally normal part of general healthcare.

People come and people go, also in associations like ours. So it is very important to keep a sharp focus on the issues, the challenges – and the solutions. This will ensure continuity in our fight, benefit our 3 associations and – not least – the millions of people in Europe with hearing loss. On a personal note, I must say that my cooperation with partners in the Triangle has been one of the most inspiring and rewarding in my almost 9 years with EHIMA. We have always listened to each other's arguments, always with genuine interest and mutual respect. I look forward to having many of my "work partners" also as personal friends in my – hopefully – long retirement.

*Søren Hougaard*



## New **EU Regulation** coming into force 26 May 2020.

Yet, another result of the joint lobbying of EFHOH and AEA at the European Commission to improve the current legislation in provision of hearing care and hearing aids in EU from directive to regulation. Where directive simply sets out goals for Member States, which leaves freedom for countries to decide on adoption into their laws, the regulation leaves no room for different interpretation and must be applied word for word to provide harmonisation across the EU.

This is an important step in the right direction in securing consumer protection in addressing sales of PSAPs marketed as hearing aids as well as recognising that provision and use of hearing aids (as medical devices) is inseparable from intervention of hearing care professionals. EFHOH and AEA also addressed the safety of PSAPs, which has been taken seriously by the regulatory bodies from the USA, ITU to EU. This is a great example of how combined efforts of professionals working with hard of hearing advocates can bring right results.

The pinnacle of this effort is the EU leading in consumer protection with above mentioned regulation which follows the Essen Declaration 2015 .

However, the work is not finished here. Advocates working at the national level in Member States will be in better positions to request enforcement of the regulation but

they will still need to be vigilant and monitor the situation. Today and during the next 3 years, the member states are implementing the Medical Device Regulation into local laws and in this implementation they should involve both the users and the professionals, so please be ready to respond to this request. Should you have any questions in relation to this development, please contact me directly @ [vice.president@efhoh.org](mailto:vice.president@efhoh.org)

The link to the full EU document can be found here <http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=O-J:L:2017:117:TOC>

Lidia Best  
Vice- President EFHOH

Footnotes:  
[https://docs.wixstatic.com/ugd/c2e099\\_69a6a905048441b29a8f4a2ba1e12f50.pdf](https://docs.wixstatic.com/ugd/c2e099_69a6a905048441b29a8f4a2ba1e12f50.pdf)  
[https://docs.wixstatic.com/ugd/c2e099\\_13e3b120ba-6b4518a5567ce2287cc593.pdf](https://docs.wixstatic.com/ugd/c2e099_13e3b120ba-6b4518a5567ce2287cc593.pdf)





# Living with a Cochlear Implant

Minister of Social Affairs and Health, Pirkko Mattila, opened the Euro-CIU 2017 symposium on Thursday. She stressed the importance of accessibility for the hearing impaired. In her opinion the biggest obstacle to inclusion is negative attitudes. Mattila said that Cochlear implants are truly important as they enable children to study and later to participate in working life.

President of the Euro-CIU Teresa Amat opened the English-speaking part of the symposium on Friday and stressed that much has been achieved through European co-operation. As an example she mentioned the growth in the number of binaural implantations in different European countries. Amat emphasized the importance of education and training not only for children but also for adults with CI.

Several lectures were given at the symposium on music and its benefits to people with hearing loss. According to brain researcher Minna Huotilainen, music develops brains and speech can be better recognized. Numerous workshops introduced the practices of teaching music to people with hearing loss.

One of the key themes of the symposium was multilingualism. Professor Åsa Palviainen of the University of Jyväskylä said that multilingualism is common, although today there is a very strong single-language stereotype in society. People do not know that they are actually multilin-







Kuuloliitto ry



EURO-CIU EUROPEAN ASSOCIATION OF COCHLEAR IMPLANT USERS

gual, which means that they are capable of speaking more than one language.


Audiologist Sari Mykkänen from the University Hospital of Tampere emphasized the importance of peer support after the CI-operation. Researcher Anniina Lavikainen and project coordinator Ilona Maula-Tervo from FFHOH told that the information about CI-users in Finland has so far relied largely on medical research and on personal experiences on the other hand. The survey of the project in 2015 showed that peer support is needed clearly throughout the whole process of implantation.

The Euro-CIU symposium was held for the first time in Finland and was organized by LapCI ry (The Finnish Association of Cochlear Implant Recipient Children), the committee of CI users/FFHOH and Euro-CIU.

eurociu.implantecoclear

LKEA TALO





**IFHOH President's Message  
for EFHOH:**

# **SDGs as Instruments for Change**

## **HISTORY IN THE MAKING AT WHO**

This is a historic month. For the first time in 20 years, the World Health Organization General Assembly, which is meeting in Geneva from the 22-31 of May, will be presented a resolution for a new action plan for the prevention of deafness and hearing loss. Although the title of the motion refers to prevention, the impact of the motion on hearing health care can be expected to be much broader. The previous motion, WHA 48.9, was adopted in 1995.

The motion has been in the making for several years and IFHOH supports the initiative and WHO's efforts to advance awareness of hearing loss and to develop strategies and support for improving conditions for persons with hearing loss. Among these initiatives are World Hearing Day of March 3 and its Make Listening Safe initiative launched in 2015. We are involved in these initiatives. As well, we have been involved in some of the groundwork to the motion, including presenting at a side event during the 2015 WHO General Assembly, on the topic of Action for Better Hearing held May 18 in Geneva.

In May 2016 WHO's Executive Board, at its 139th session, adopted resolution EB139.R1, which recommended to the Health Assembly the adoption of a resolution relating to deafness and hearing loss. This year, the motion is Agenda Item 15.8 and the report to the Assembly can be found on the WHO website at [http://apps.who.int/gb/ebwha/pdf\\_files/WHA70/A70\\_34-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA70/A70_34-en.pdf).



I also reviewed the comments from various member states at the Executive Board meeting of May 30, 2016, all of which were in support of the motion with key points being:

- The magnitude of the problem of hearing loss and its economics and social implications are enormous
- A holistic approach should be taken, integrating strategies for ear and hearing care into health systems.
- Hearing loss affects all countries but particularly low-income countries where early identification and treatment is often lacking and necessary immunizations are not always available.
- Hearing loss prevention of noise-induced hearing loss in the workplace and through unsafe use of audio devices is essential.
- Poor hearing exacerbates problems faced by persons who are aging and its relationship to dementia is concerning.

- Appropriate, high-quality hearing devices are inaccessible to many because of supply and pricing constraints.
- Building capacity is necessary through trained professionals, adequate health information systems to provide evidence for monitoring, implementation and policy-making and a standardized approach for the prescription and use of various hearing devices.

The adoption of the resolution will be an opportunity for our community to work closely with our national governments to taken action for better hearing and for IFHOH to work, on your behalf, at the international level with WHO.

These are exciting, historic times.

Dr. Ruth Warick  
President, IFHOH

*// These are exciting, historic times.*



# International Accessibility Conference on Hearing Loops and Hearing Technology Future Loops

6th to 8th October 2017 in Berlin, Germany

Dear EFHOH Members:

Deutscher Schwerhörigenbund e.V. will carry out this international IFHOH Conference. The overall aim of the conference is to present the latest Loop technology, provide information of the many forthcoming alternatives and discuss their benefits.

The Conference is designed for anyone interested in accessible technology for people with hearing loss and in sound systems.

Accessibility in public places for hearing impaired people will be available when sound engineers, architects, audio/visual designers, installers and other responsibilities raise awareness of consumer interest and demand for this technology and attendees can advocate more effectively for the wide availability of this technology within their own communities. This is what the motto Future Loops stands for.

The Keynote Speakers of the Conference represent the three Conference topics: Technical development – Experience – Motivation







### 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 and the National Hearing Loop Advocate with the Hearing Loss Association of America.

### Peter Dieler

A counselor, coach and mediator for hearing issues working as Head of Audiotherapy, MEDIAN Klinik am Burggraben, Bad Salzuflen, Germany

#### Further designated Speakers:

- Volker Albert, Deutsche Tinnitus-Liga, Germany
- Avi Blau, IFHOH, Israel
- Dieter Fricke, ReSound, Germany
- Bernadette Fulton, Phonak, Germany
- Siegfried Karg, pro audito, Swiss
- Thomas Kaufmann, OTOJOY, USA
- Juha Nikula, Qlu, Finland
- Julian Pieters, Ampetronic, United Kingdom
- Aida Regel Poulsen, EFHOH, Denmark
- Andrew Thomas, Contacta Systems, UK
- Anna Kain Wyatt, The HODA Project, Sweden

Please find the full list of speakers and abstracts of the presentations on the DSB Conference homepage end of August 2017.

### Conference Schedule

Thursday 5th October  
Evening Welcome for international guests

Friday 6th and Saturday 7th October  
The Main Conference, Exhibition and Workshops

Friday Evening entertainment  
guided Berlin Highlights tour with dinner

Saturday Evening entertainment in a restaurant nearby

Sunday 8th October  
Cultural programme

The Conference will be accompanied by an exhibition on the days of the main Conference 6th and 7th October. Suppliers, service providers and specialists of emerging hearing loop technology, hearing aid and cochlear implant technology, manufacturers of assistive listening devices and other companies will feature or promote their services and products.

A complementary Workshop program will enhance the exhibition and provide opportunity for demonstrations and discussions.

Please register until 20th August 2017 (see next page).

Conference Center - Hotel Steglitz International  
Schloßstraße/Albrechtstraße 2, 12165 Berlin  
Tel: +49(0)30-790050, Internet: [www.si-hotel.com](http://www.si-hotel.com)  
For accommodation a room allotment is available.

Please find more information, the registration form and the hotel booking form on the DSB Conference homepage <http://www.schwerhoerigen-netz.de/IFHOH-2017/english>

For any questions please contact the DSB Conference Manager  
Gudrun Brendel: [IFHOH-2017@schwerhoerigen-netz.de](mailto:IFHOH-2017@schwerhoerigen-netz.de)

The Conference is sponsored by Germany's largest funding organization in the social sector, the Aktion Mensch. We would like to thank the Aktion Mensch most sincerely for the generous support. [www.aktion-mensch.de](http://www.aktion-mensch.de)

Looking forward to welcome you in Berlin.

Renate Welter  
Vice-President of DSB



## 4th International Accessibility Conference on Hearing Loops and Hearing Technology in Berlin, Germany October 6 - 7, 2017

### YOUR PERSONAL INFORMATION

<b>Last Name:</b>	<b>First Name:</b>
<b>Mr/Mrs/Ms/Dr /Prof:</b>	
<b>Name of Association:</b>	

### ADDRESS

<b>Street:</b>	<b>City:</b>
<b>Country:</b>	<b>Post Code/ZIP:</b>
<b>Email :</b>	<b>Fax:</b>

### ACCOMODATION

Please note that you have to care for your own accomodation

Pre-Reservation for rooms of conference guests have been placed at the Hotel Steglitz International.  
 Passwort: IFHOH Loops. Reservation according to availability.  
 Singlerooms are available at the rate EUR 92, doublerooms EUR 117 per room per night.

### BOOKING PACKAGE

#### Variant A, conference fees EUR 180.00

- \* Attendance on the Conference: October 6 - 7, 2017 with conference material
  - \* Catering during the whole Conference (with lunch and refreshments throughout the conference)
- Please mark an X here

#### Variant B, conference fees EUR 240.00

- \* Attendance on the Conference: October 6 - 7, 2017 with conference material
  - \* Catering during the whole Conference (with lunch and refreshments throughout the conference)
  - \* Guided Berlin Highlights Bustour with dinner friday evening
- Please mark an X here

### SIGN- ON AND PAYMENT OPTIONS

This registration form should be submitted to:

Deutscher Schwerhörigenbund e.V.  
 Sophie-Charlotten-Str. 23 a, 14059 Berlin,  
 Germany  
 Mail: IFHOH-2017@schwerhoerigen-netz.de  
 FAX: +49 30 47541116

**Closing date for registration: August 20<sup>th</sup> 2017**  
 You will get a bill after registration.

**Date**

**Signature**

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## The "2017 Award for the Best Subtitled Movie"

As you know (see the June 2016 issue of EFHOH Newsletter), ARDDS is awarding a « Prix du meilleur film sous-titré » to the "Best Subtitled Movie" of the year, hoping to create awareness amongst media and all interested people (professionals, spectators and politicians) so that they fully understand that movies do have to be subtitled for deaf and hard-of-hearing persons. This initiative is gaining recognition, as more and more partners support it – last but not least, the CNC (« Centre national du cinéma et de l'image animée »), a public administrative organization under the authority of the French Ministry of Culture and Communication.

A national jury voted after viewing a total of 86 movies released in France in 2016: the winner is « La fille de Brest », by Emmanuelle Bercot. This movie, based on the book "Mediator 150mg", tells the true story of Irène Frachon who broke the Mediator scandal: in a hospital in Brest, a lung specialist establishes a direct link between suspicious deaths and the consumption of Mediator, a drug that had been on the market for 30 years. This thrilling David-versus-Goliath story is not the story of Mediator, but the story of an exceptional woman's fight. It climaxes in a victory for truth and critics have compared it to "Erin Brockovich", French style.

The lead actress, Danish star Sidse Babbett Knudsen, has been nominated for the "Best Actress" 2017 César for her outstanding performance. She is also well known for playing Birgitte Nyborg in "Borgen". Her name was suggested to Emmanuelle Bercot by ... Catherine Deneuve.

For practical reasons this award only concerns French-speaking movies screened in France, but we would enjoy exchanging ideas or even collaborating with other hearing loss associations in other countries speaking different language, as needs certainly are similar everywhere.

You will find up-to-date information on this award on our Website: <http://vfst.ardds.org>; if you find it easier to read, you can also view it "machine-translated": [http://translate.googleusercontent.com/translate\\_c?tl=en&u=http://vfst.ardds.org](http://translate.googleusercontent.com/translate_c?tl=en&u=http://vfst.ardds.org)

1. Please note that while the French original title of the movie is « La fille de Brest », the international title appears to be: "150 milligrams".

## **Dutch hospitals listen to hearing impaired people**

Text: Martine van Hulst

**Patient-kindness in hospitals is high on the agenda nowadays. Yet in dealing with hearing impaired patients there is still a lot to improve. We learned this during the Experience Sessions with the theme “Communication with physicians”. Dutch NVVS-volunteer Martine van Hulst expressed in an article the problems, solutions and tips that were brought up during these sessions. Her article led to the onset of a successful project in the Netherlands. This project leads to improvement of the attitude, from (medical) desk clerk to doctor, while communicating with a hearing impaired patient.**

### **Experience Sessions**

The Dutch Association for the hearing impaired (Hoormij/NVVS) organizes small sessions where persons with a hearing problem share experiences and tips on a specific theme. A lot of persons showed interest in the theme *Communication with physicians*. Therefore multiple sessions were held. The participants in these sessions were critical about the communication with doctors, nurses and health authorities, and also about themselves. "Can I expect that physicians who hear, understand what I need?" asked one participant wondering. "Initially I did not even know it myself. I think it is not unwillingness of a doctor. During their training physicians learn almost nothing about communication skills and of course most of the attention is paid to the numerous diseases. "

The participants spoke about the bottlenecks in communication where they themselves had run across in a hospital or other healthcare facility. For example: while sitting in the waiting room an inaudible name was called from a distance or a facemask muted the voice of a doctor on a very critical moment in the operation room. Some experiences were really shocking.

### **Project *Communication with physicians***

Declarations of support after the publication of the article made it clear that something should be done. NVVS-volunteers Willem Dekker and Martine van Hulst analyzed all the mentioned problems. They made a list of the often simple suggestions that were mentioned. In most cases these suggestions turned out to be real good solutions. The most focal point became clear, which is raising awareness of the communication problems through recognition and acknowledgment. A second important priority is providing practical solutions. Often simple cheap solutions are available.

Voluntary project members started visiting hospitals and other healthcare facilities. They talk with staff members who are in the position to bring about change in their organization. The volunteers bring a positive message with ideas for improvement. They leave a short brochure that covers the whole content of the mission. The volunteers are truly welcome and during their visits and the conversation they find interested listeners. The problems outlined are always recognized.

### **Challenges**

One of the challenges is to find an entrance to the right person in a hospital who can further spread the message. Writing e-mails or letters did not work. The only proper way to create an entrance to the right person turned out to be through personal contact. Another challenge is the amount of hospitals. In the Netherlands there are



362 hospitals and even more other healthcare facilities. It is impossible for a few volunteers who are qualified for the job to visit them all.

### Goals and changes

One of the most important goals is the adaptation of patient records. Hospitals need to realize a pop up which appears directly after opening the record: "Patient is hearing impaired. Look at him while speaking. Make sure the message is understood." A leading Dutch academic hospital immediately acknowledged the value of this suggestion and promised realization.

Some hospitals ask for an article on their internal blog so all the workers can get aware of the problems and the improvement suggestions. Other hospitals invite the volunteer for a lecture to a larger audience, for example to their entire staff or to employees of a specific department, such as the geriatric ward. There are even hospitals where, after a lecture, on every desk this text appeared: "Are you hearing impaired? Tell us. We do take note."

Also great ideas, found in one hospital, are taken to other hospitals. For instance: the bedbox. This is a little box, which is attached to the bed when a patient goes to surgery. Due to the bedbox communication is accessible as long as possible because just at the last moment before an operation the hearing instruments are put into the bedbox. After an operation the hearing aids are immediately available. Hospitals embraced this idea after volunteers told them about it.

Changes become visible. Those responsible in hospitals realize that a topic is brought to their attention of which they have never consciously thought about in terms of solutions.



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## Hire an EFHOH speaker!

Invite us to talk. We can travel to your event to present and share our work and lobbying experiences.

We may present about IFHOH Human Rights Toolkit and Prague Declaration, the UN Convention on the Rights of Persons with Disabilities, including our subtitled lobbying work.

EFHOH representatives will never charge for their presentations, however we may request for travel and accommodation to be covered by the inviting party.

Please contact us at [office@efhoh.org](mailto:office@efhoh.org)



# Ljubljana 2018; IFHOH BGM, EFHOH AGM, Conference “Accessibility Removes All Barriers”

Deaf and Hard of Hearing Clubs Association of Slovenia are glad to invite you to IFHOH BGM, EFHOH AGM and Conference in our capital Ljubljana on May 11th to 13th 2018.

Topics at the conference will focus on adaptation and accessibility of both, the physical environment as well as the people living in it. We believe that understanding the problem of hearing loss allows a better understanding of the need for accessibility and integration into everyday life.

We are confident that the conference will not only be interesting and informative for you, but it will also show you how to raise awareness of the environment and provide opportunities for the exchange of good practices among participants.

In Slovenia, deaf, hard of hearing, cochlear implant users and deafblind people of Slovenia are joint together in the Deaf and Hard of Hearing Clubs Association of Slovenia (acronym ZDGNS) -

ZDGNS is a non-governmental expert organization that endeavors for equal status and the rights of people with hearing loss and collaborates with competent governmental agencies and bodies.

Deaf and hard of hearing people established first club in Slovenia almost 90 years ago, so we are a relatively old organization. But specific hard of hearing board was established 30 years ago and in the last three

years we are also active in the field of cochlear implants.

Association is an umbrella organization uniting 13 member clubs organized across the country with almost 4600 members (more than 3100 hearing aids users and more than 50 CI user)

Fundamental scope of the Association is creating jobs and conditions for full inclusion of people with hearing loss in daily jobs, working environment, and social life. In the past few years we are focused to remind people around us of the needs of the various adjustments for people with hearing loss. Association has its own informative sources, including video production, broadcasting, and a monthly newsletter

Since 1999 ZDGNS has the status of an association working for the public interest in the field of social care and has been registered as a representative disability organization.



In order To host the BGM, AGM, and to organize the conference we have booked M hotel in Ljubljana <https://www.m-hotel.si/>. It is located between the Ljubljana ring road and the city centre providing a fast connection to the city center, airport and other tourist destinations and attractions in Slovenia. The city center is only a 5-minute drive away with public transportation and the closet bus stop is 50 metres away from the hotel. Below are some usefull informations about living in Ljubljana during your visit:

Airport info: <http://www.lju-airport.si> (transport from airport to Ljubljana - shuttle /9€, taxi 20-25€, bus 4,10 € - it takes you not more than 30 minutes). But we are not far away from the airports in Austria, Italy, Hungary and Croatia.

Living in Ljubljana: <https://www.visitljubljana.com>  
Traveling around the city: <http://www.jhl.si/en/single-city-card-urbana>

Board meetings of IFHOH and EFHOH will be organized on Thursday in the meeting room in ZDGNS, which is near the M hotel. In the late afternoon we

will show you our beautiful city and after that we will have a reception and a social evening. Conference day will take place on Friday, May 11th, and it will be followed by IFHOH AGM and EFHOH BGM on Saturday.

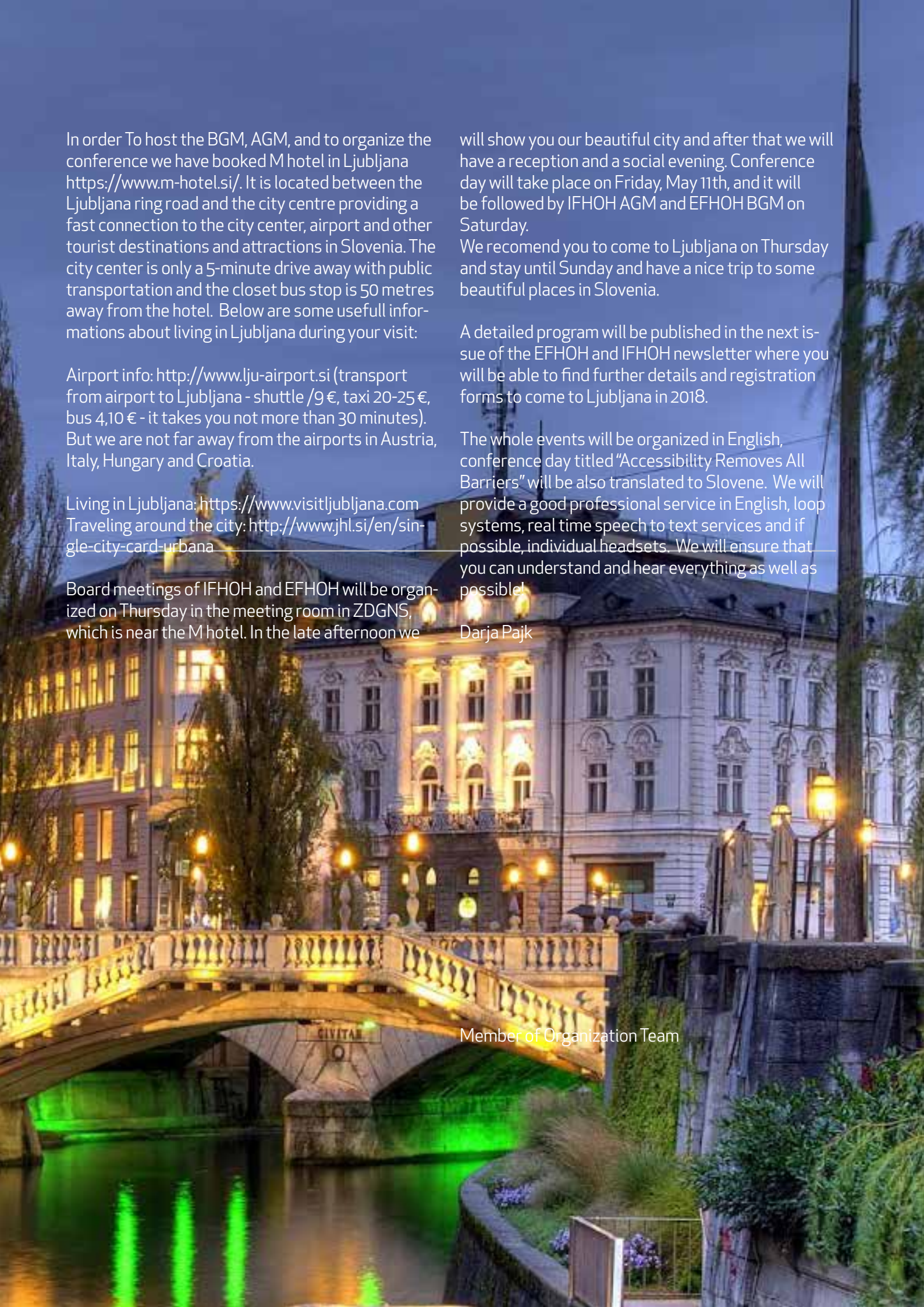
We recomend you to come to Ljubljana on Thursday and stay until Sunday and have a nice trip to some beautiful places in Slovenia.

A detailed program will be published in the next issue of the EFHOH and IFHOH newsletter where you will be able to find further details and registration forms to come to Ljubljana in 2018.

The whole events will be organized in English, conference day titled "Accessibility Removes All Barriers" will be also translated to Slovene. We will provide a good professional service in English, loop systems, real time speech to text services and if possible, individual headsets. We will ensure that you can understand and hear everything as well as possible.

Darja Pajk

Member of Organization Team





## BUILDING AN INCLUSIVE DISABILITY MOVEMENT FOR THE FUTURE

EDF's Annual General Assembly (AGA) in Madrid, Spain, this weekend brought together over 200 participants, including AGA delegates, observers, partners, guests and members of the global disability movement. The meeting was hosted by EDF Spanish members, CERMI and ONCE Foundation. A conference was also organised in the framework of the AGA to mark EDF's 20th anniversary.

Entitled '20 years later: Building an inclusive disability movement for the future', the conference was an opportunity to recall the great achievements of the disability movement in the last 20 years, but also to identify the challenges ahead and how the disability movement should address these challenges.

Opening the meeting, EDF President, Yannis Vardakastanis, recalled the advances that persons with disabilities have experienced in their lives in the last 20 years. He also highlighted the great importance of the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) by the European Union (EU). However, he also talked about the responsibility of the EU to stand by the side of its citizens and improve the living conditions of all people including those with disabilities. "We have seen the adoption of many EU laws and policies that protect, promote and ensure the rights of persons with disabilities in areas such as passengers' rights, structural funds, employment, web accessibility etc. EDF believes in a strong and united Europe and expresses its support to the EU to be an inclusive place where all human rights are protected and people with disabilities are included in society without discrimination. EU should protect people with disabilities from austerity measures that create more poverty and inequality", said Yannis Vardakastanis.

Moreover, EDF President raised the importance of the active involvement of persons with disabilities through their representative organisations in line with the motto of the disability movement: 'Nothing about us without us.' "There are cases at national level that organisations of persons with disabilities are not supported or not allowed to do their work. The EU and its Member States have the obligation, under the CRPD that they have ratified, to ensure that the organisations of persons with disabilities are involved and consulted. Capacity building and funding should be secured, and barriers should be removed", underlined Yannis Vardakastanis.

CERMI President, Luis Cayo Pérez Bueno, underlined that we need a strong and united Europe that hears the needs of all people with disabilities including refugees with disabilities. CERMI President said that people with disabilities are often deprived of their legal capacity, the right to vote,



the right to education and other things that are essential in life due to lack of accessibility. He also stressed that women and girls with disabilities are at high risk of experiencing discrimination, violence and forced sterilisation.

ONCE and ONCE Foundation President, Miguel Carballada, explained that ONCE's Sports and Cultural Centre, in which EDF AGA was taking place, used to be a school for the blind. "Today 7,500 blind children in Spain go to ordinary schools together with their peers without disabilities. Inclusion, solidarity and unity are what ONCE has been fighting for throughout its history", he said.

The President of Group III (Various Interests) of the European Economic and Social Committee (EESC), Luca Jahier, presented the work that the EESC does to promote disability rights and the implementation of the CRPD. He also called on the EU to develop a clear and comprehensive disability rights agenda following the recommendation by the UN Committee on the Rights of Persons with Disabilities. "When I think of the disability movement, I think of values, rights, people and sustainable development", he concluded.

On Saturday 13 May 2017, speakers also included the European Commissioner for Employment, Social Affairs, Skills and Labour Market, Marianne Thyssen, the UN Committee on the Rights of Persons with Disabilities Member, Ana Peláez, Narváez, and the Member of the European Parliament, Helga Stevens.

Human Rights Watch also spoke about how persons with disabilities have been involved in the global human rights movement.





In her speech Ana Peláez Narváez talked about those who face a high risk to be left behind, such as women and girls with disabilities, children, and persons with invisible disabilities. “Do you think all people with disabilities have the right to vote or the right to inclusive education? Or that all women with disabilities have the right to be mothers?”, she said concluding that “all rights have to be a reality for all people, not some rights for some people”.

On Sunday 14 May 2017, the discussion focused on what the European disability movement needs to do to continue fighting successfully for equality and social justice in the future. What are the opportunities we have? What are the challenges? Who are our allies?

The panelists here included Nujeen Mustafa, a young refugee with disability, Klaus Lachwitz, Secretary of International Disability Alliance, and representatives from Civil Society organisations, such as the European Women’s Lobby, the European Youth Forum and Age Platform Europe. Nujeen Mustafa talked about the challenges that refugees with disabilities face due to the lack of accessibility in the refugee camps that makes even basic things like entering the toilet impossible. “It’s shocking that the camps are not prepared to receive also refugees with disabilities because it is easy to imagine that many refugees get a disability during this difficult trip”, Nujeen Mustafa said emphasising that refugees with disabilities should not be forgotten. Find out more Nujeen’s story in our article ‘Fleeing Syria in a wheelchair’.

EDF AGA adopted important resolutions on the Accessibility Act and on the Marrakesh Treaty, as well as a report on Forced Sterilisation and a declaration with the vision of the disability movement and a plan for action for the coming years.

EDF AGA also elected EDF President, Board and Executive Committee.

## EDF TOOLKIT ON THE WEB DIRECTIVE

The Directive on the Accessibility of Websites and Mobile Applications of Public Sector Bodies (known as the Web Directive) was adopted in October 2016. The European Union (EU) Member States will have until September 2018 to transpose this EU legislation into national law. This means that they will need to adopt new legislation or to

reform existing laws to comply with the objectives and provisions of the Web Directive, which will ensure that all public sector bodies’ websites and mobile applications will be accessible for persons with disabilities.

That is why, it is extremely important that EDF members engage with their national governments to make sure that they get the best out of this Directive, so that the misinterpretation of some articles and exemptions will be prevented. Moreover, the Web Directive can also be extended at national level and includes certain mechanisms to ensure its success. Therefore, to assist its members, EDF publishes a toolkit aiming at providing the key information about this EU legislation as well as advices for the transposition phase. Now it is time to achieve at national level, what we have been advocating for at the EU institutions for the past years.

As presented at EDF’s Annual General Assembly (AGA) in Madrid, we have prepared a toolkit to help you with your campaigning on the Accessibility Act. It has useful information on how to best use social media and other actions that you can organise to ensure that the EU decision-makers adopt the Accessibility Act we want!

For more information contact [marie.denninghaus@edf-feph.org](mailto:marie.denninghaus@edf-feph.org) and visit the Accessibility Act section on the EDF website for more supporting material.

## LOTTERY TICKET FOR THE 20 YEARS OF EDF

ONCE, the National Organisation of the Blind in Spain, launched a lottery ticket dedicated to the 20th anniversary of EDF. This lottery ticket aims at raising awareness about the advances in disability rights in Europe in the last 20 years and the importance of a strong and united disability movement.

## BUILDING AN INCLUSIVE DISABILITY MOVEMENT

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Entitled '20 years later: Building an inclusive disability movement for the future', the conference was an opportunity to recall the great achievements of the disability movement in the last 20 years, but also to identify the challenges ahead and how the disability movement should address these challenges.

## ACCESSIBILITY ACT: BUSINESS OVER PEOPLE?

The European Parliament's Internal Market Committee (IMCO Committee) adopted a very disappointing report on the Accessibility Act in yesterday's vote.

The IMCO Committee has favoured business demands over the rights of people, including persons with disabilities, older people and all consumers. This fully contradicts all previous statements by the European Parliament on the Accessibility Act and in particular the European Parliament's resolution of 7 July 2016. The report is watering down the European Commission's proposal to such an extent that there is a risk that the Accessibility Act may be meaningless for millions of people in Europe.

This is a moment in Europe where citizens need to see the European Institutions adopting laws and policies which are going to benefit ordinary people. We call on all the Members of the European Parliament (MEPs) to substantially amend the IMCO Committee's report in the plenary in June and to promote a strong and ambitious Accessibility Act.

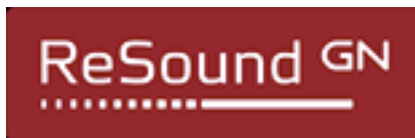
The IMCO Committee's report as it was voted yesterday:

- Completely excludes microenterprises from making their products and services accessible to all people;
- Limits the link to public procurement and European Union (EU) Structural Funds;
- Does not fully address the accessibility of the built environment;
- Deletes the definition of "persons with functional limitations";
- Exempts both Small and Medium Enterprises (SMEs) and microenterprises from the notification obligation to the authorities;
- Limits the application of the Act on transport services;
- Grants longer transition times to self-service terminals;
- Limits the accessibility requirements for audiovisual services to only websites and mobile applications.

What does that mean in practice?

- The exemption of microenterprises means that many e-commerce services and e-books of small publishers will be inaccessible; millions of people in Europe, including persons with disabilities, will continue being excluded from buying things online or reading e-books.
- Buildings do not have to be accessible, if Member States show they already have any kind of accessibility legislation in place, even though this legislation might be very limited or insufficient in practice. Therefore, millions of people in Europe will continue facing barriers to enter a bank, a school, a train station etc.
- It will be possible that EU funding and taxpayer's money are used to pay for a school building that is not accessible, as there are still no binding accessibility requirements. Entering a school will, thus, continue being impossible for many children with disabilities in Europe.
- A "small" company of up to 250 employees can continue making inaccessible products without having to notify the authorities, if they consider that making their products and services accessible would be too much of a burden for them. In practice, it will be therefore difficult to check if they are applying the accessibility requirements correctly.
- When a company calculates whether making their product accessible would cost them too much, they only have to estimate the number of persons with disabilities that would be "directly affected". This excludes older people, people that have temporary impairments e.g. following surgery or with a broken leg, as well as other consumers that benefit from the accessibility features.
- Even if they are not accessible, cash machines (ATMs) or ticketing machines can still be used until the end of their economic lives; they don't have to be replaced by accessible ones which would make it possible for all people to use them to withdraw money or buy a ticket.
- Every TV broadcaster will decide themselves how their accessibility services will be provided to their audience and of what quality these will be. For example, when it comes to subtitles for the deaf and hard of hearing people, or the audio description for blind people. Furthermore, important aspects on audiovisual services, such as the Electronic Program Guides, will remain inaccessible so persons with disabilities and other people won't be able to use them.

*EFHOH would like to acknowledge our sponsors generosity helping us continue our efforts in European advocacy*



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## EFHOH MEETINGS 2017:

2017	2017	2017	2017
24-28 June	Paris	IFOS Congress	Lidia
3-4 July	Geneva	WHO stakeholders meeting	Lidia
October or December	Brussels	Platform meeting	Aïda and Marcel
4-5 October	Berlin	IFHOH board meeting	Marcel
6-7 October	Berlin	IFHOH Loops Conference	All board members
8 October	Berlin	EFHOH board meeting	All board members
24 October	Copenhagen	Hear-It AGM	Aïda and Marcel
29 October	Helsinki	IFHOHYP AGM 2017	Juha
November/December	Brussels	4 <sup>th</sup> European Parliament of Person with Disabilities	Marcel
December	Brussels	European Day of Persons with Disabilities 2017	Aïda and Marcel
2018	2018	2018	2018
11-12 May	Ljubljana-Slovenia	EFHOH AGM	All board members
5 June	Barcelona	Understanding Quality in Media Accessibility (UMAQ) Conference	Marcel

Version 08-06-2017

## EFHOH - European Federation of Hard of Hearing People

The European Federation of Hard of Hearing People consists of National Associations of/for Hard of Hearing and Late-Deafened People, Parents' Organisations and Professional Organisations.

EFHOH comprises the European members of the International Federation of Hard of Hearing People (IFHOH) and was established in 1993. It has its own board and secretariat. The federation has non-profitable and benevolent aims and it is a non-political and non-sectarian organisation. EFHOH is a general member of the European Disability Forum (EDF). We also work in good co-operation with IFHOH and our official language is English.

The Board members of the EFHOH carry out their work on an honorary basis.