

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

Deadline for the next
newsletter is August 15.th
/2016.

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NEWSLETTER

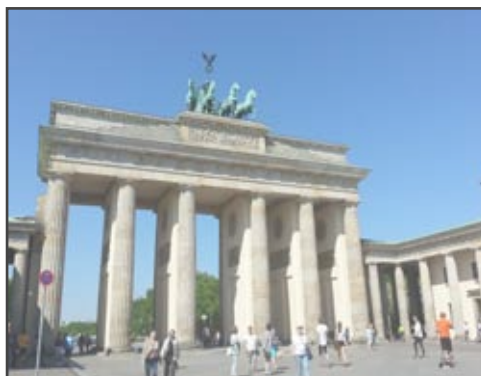
EFHOH

JUNE 2016



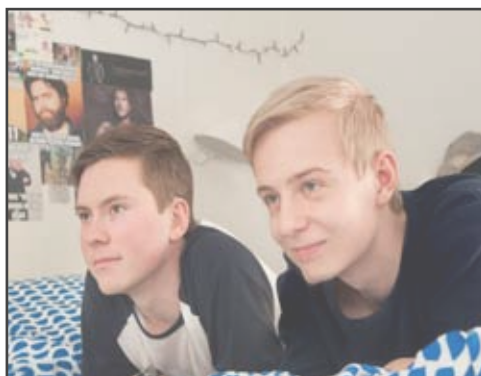
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IT IS COOL, WHEN PEOPLE FORGET, I DO NOT HEAR WELL!

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European Federation of Hard of Hearing People



Marcel with Celia Wolloughby and Juha Hietala (new member of the EFHOH board)

EFHOH President letter

Dear Members,

We as EFHOH board members can look back at a busy and interesting period after our last Annual General Meeting in Paris.

Our vice president Lidia Best was in Cernobio by Lake Como in Italy at the beginning of June for the HEAL 2016 conference. HEAL = Hearing across the Lifespan and the theme of the conference was "Early intervention is the key to better care". Lidia was one of the speakers and gave a presentation about the results and recommendations of the European standard on services offered by hearing aid professional's survey, which EFHOH carried out last year. Many delegates at the conference spoke to us and supported our work on quality of hearing care and rehabilitation. Thanks to our members who took part in the survey! During the same weekend, EFHOH's secretary Aida and I had a nice and interesting meeting with Kim Ruberg and Soren Petersen of Hear-It. The topic of this meeting was informing each other and discussing how we can have a stronger co-operation between Hear-It and EFHOH in relation to Hearing Awareness. More information about Hear-It on: www.hear-it.org.

Some weekends ago, Aida our secretary was one of the speakers at a seminar of VDNR – the late deafened in

Scandinavia. This seminar was in the Danish Disability House, where some of you had participated in the IFHOH UN CRPD workshop.

EFHOH AGM 2016:

It was great to meet most of our members in Paris at the EFHOH Annual General Meeting 2016. We thank the members and the board of BUCODES / France for organizing this event. Also we want to say thanks to all the speakers for their interesting presentations and thanks to all the sponsors who supported this event.

We also need to inform you that our treasurer Richard Darbéra has left the board for personal reasons. We are happy that Ritva Liisa Schädling (Germany), the former treasurer, will be our interim treasurer until our next AGM in Dublin. You can read more about the next EFHOH AGM 2017 in this EFHOH newsletter but please make a note in your agenda/program for the 2017 May 5-7 weekend for the Dublin EFHOH AGM.

European Disability Forum (EDF):

Some weeks ago, Lidia and I had an excellent opportunity to give a Hearing Awareness workshop to the members of the EDF staff in Brussels. We split our workshop into two parts, the first part of the workshop was about "what is hearing loss and the impact of hearing loss on the life of



Meeting with Hear IT (Marcel, Aïda, Søren Petersen and Kim Ruberg)

hard of hearing people". The second part of the workshop was focused on the question: "what is EFHOH and what are their activities and work at the European level?" It was very good and interesting to answer all of the questions from the EDF staff members and discuss with them the different topics and issues on how to make Europe more accessible for hard of hearing people.

Together with Celia Willoughby (Irish Hard of Hearing Association) and Juha Hietala (our new EFHOH board member) I attended the EDF AGA 2017 in Dublin. You can read more about this event in Juha's article.

IFHOH BGM and World Congress 2016:

Coming soon in Washington D.C. is the IFHOH BGM and the IFHOH World Congress 2016. We as the EFHOH board hope to say hello to you and we hope that you have an interesting and nice IFHOH World Congress. On the website of HLAA www.hearingloss.org you can find more information.

Follow us:

It is great when you follow us via social media on Facebook and Twitter. Our addresses are:

EFHOH	@efhoh
Marcel Bobeldijk	@marbob32
Lidia Best	@best_lida
EDF	@Myedf
EDFaccess	@EDFaccess

It will also be beneficial if you share the EFHOH newsletter with your volunteers and members who are interested in EFHOH and European disability movement topics.

If you have an article for one of the next EFHOH newsletters that we will publish in the future, please send it to us!

Summer holiday:

Dear EFHOH friends, 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 in Europe. Enjoy the diverse European bouquet of people, and culture. This European bouquet is not complete without European flowers such as the Spanish Pink, the French Fleur-de Lys, the Greek Acanthus, the Danish Marguerite, the German Cornflower, the Austrian Edelweiss, the Croatian Iris, the Dutch Tulip and of course, the English Rose.

Have a happy and sunny summertime!

Marcel Bobeldijk



Looking Back to the EFHOH Annual General Meeting and the «Getting Informed About Hearing Loss» Conference day

The 2016 Annual General Meeting of the European Federation of the Hard of Hearing (EFHOH) was held on 1, 2 and 3 April 2016 in Paris. Saturday April 2nd was dedicated to a day of conferences titled «Getting Informed About Hearing Loss». The Bucodes SurdiFrance was in charge of the organization of this edition. The event went well and returns are enthusiastic.

The event was held at the International Residence of Paris. 49 delegates and observers from 16 European countries gathered on Friday for the EFHOH AGM, followed by a dinner and a night cruise on the Seine River. Saturday was dedicated to a day of conferences, open to all, upon registration, on the theme «Living Well with hearing loss.» More than 200 people attended the event. All lectures were translated into French and English and accessible to the Hard of Hearing. Individual magnetic loops were made available to participants and simultaneous transcript was streamed on two displays, in English and French.



Paris by night on Friday, 1st April 2016

The conference day was opened by Bruno Frachet, President of the Agir pour l'Audition foundation, Marcel Bobeldjik, President of EFHOH and Richard Darbéra, President of Bucodes SurdiFrance.



A full conference room: 220 participants attend the conference

- Audrey Sitbon from [INPES](#) (French Ministry of Health) presented the French survey on the deaf and hard of hearing people (Baromètre Santé Sourds et Malentendants = BSSM). INPES had sent to the Congress three boxes of books on BSSM results together with summarized versions in English. All this documentation has been taken away by participants. View her presentation [here](#).
- Dr. Françoise Artières presented an overview on cochlear implants starting from the experience of the [Palavas implantation centre](#) and the Montpellier University Hospital.
- Søren Hougaard, representative of the [EHIMA](#) (European Hearing Instrument Manufacturers Association) commented on the results of the Eurotrak Survey. View his presentation [here](#).
- Mark Laureyns of the [AEA](#) (Association of the European Hearing Aid Professionals) presented its actions and ways to improve the services provided by audiologists. View his presentation [here](#).
- Dr. Benoit Mongourdin presented the emergency call number **114** and future development towards full conversation. View his presentation [here](#).
- Dr. Hans Mülder [Phonak](#) spoke on the issue of «hearing in noise» from the point of view of a manufacturer of hearing aids. View his presentation [here](#).
- Renaud Perdrix of the National Information Centre on Deafness introduced [Surdi.info](#) news site.
- Finally, Dominique Dufournet of Bucodes SurdiFrance presented the future Practical Guide to properly getting equipped with hearing aids.

Stands were held by Cochlear, Unisson, Phonak, Audiofils, Surdi.info, the Association Journée Nationale de l'Audition, Access Culture, Accessens, the National Emergency Call Centre 114 and Bucodes SurdiFrance.

On Sunday morning, a guided tour of Montmartre has been proposed to the European delegates and observers.

The organizing team of 4 members of Bucodes SurdiFrance with the support of a steering committee, 9 volunteers Amiens speech therapy school and the various providers (accessibility, language, entertainment, communication, catering etc.) have mobilized to make this day a success.

Thank you to the members of the EFHOH, the stakeholders, the partners and exhibitors, the Bucodes volunteers, the students from the Amiens speech therapy school, SCOP Le Messager (accessibility), Nathalie Goussé (graphic design), Gwendal Le Flem (photo), Françoise Cognet (animation) and finally thank you to all participants often come from afar to attend this meeting.



Bucodes SurdiFrance

Maison des associations du 18ème | 15 passage Ramey (boîte 83) | 75018 Paris

Tél. : +0033 (0)9 72 45 69 85 | Courriel : contact@surdifrance.org | Web : www.surdifrance.org

Reconnu d'utilité publique, le Bucodes SurdiFrance fédère des associations de personnes malentendantes et devenues sourdes dans toute la France.



EFHOH AGM & Conference Dublin 2017

Hearing Loss Ireland extends a warm invitation to you all to come to Dublin on May 5th & 6th 2017 for the EFHOH AGM and Conference!

Hearing Loss Ireland are proud to announce that this event will be held in Ireland's capital city, Dublin, on May 5th and 6th next year and we assure you of a fruitful learning experience and a fun time too.

The theme of the conference will focus on the latest developments in helping those with hearing loss, and it hopes to address not just new technological features but also the latest ideas on the development of social and personal skills and facilities to help us cope better.

We hope to engage a range of European, North American and Irish experts to speak to us. Indeed, if you have expertise in this field and feel you could contribute, we would love to hear from you.

HLI is a small voluntary peer-support and advocacy organisation, consisting of around 250 members, and we work in partnership with a government-sponsored organisation, DeafHear, who are the main providers of services to people with hearing loss in Ireland.

As we have the backing of Failte Ireland (the Irish Tourist Board) and DeafHear we will be able to provide you with a good professional service, loop systems, real time speech to text services and individual headsets and we will do

everything we can to ensure that you can hear as well as possible.

Dublin is a compact, easily accessible city, the centre being only 10 kilometres from an international airport serving over 90 airlines flying to and from over 170 cities. We have a huge choice of accommodation at all levels and a superb range of conference facilities. It is set between the mountains, the sea and serene countryside and the centre is small and walkable.

Our plan is to use Dublin Castle and Christchurch Cathedral (both 1000 years old but with up to date facilities for hearing) as venues, to allow you to enjoy the historical ambience of our city and to learn a little of our past while also enjoying the contemporary life of today's lively city centre. Dublin is exciting, young and cosmopolitan, known internationally for its friendliness and 'craic'. We have top class restaurants, shopping and nightlife, we have a rich cultural heritage of literature, music, history, theatre and art.

Hearing Loss Ireland promises a great European Federation Conference, so look out for further details and registration forms, and come to Dublin in 2017!

Carol Robinson, Chairperson Hearing Loss Ireland 2014-2016



THE DEADLINE HAS BEEN EXTENDED TO REGISTER FOR SUMMER CAMP 2016

Hi there,

In case you haven't heard, the deadline has been extended to register for Summer Camp 2016. You've still got time!!! Register by July 1st.

1. Check out the website: <http://ifhohyp.org/summer-camp2016/index.html>
2. Like our Page on Facebook: <https://www.facebook.com/summercamp2016denmark/>

Here is a personal story from Sidsel, IFHOHYP President, of her experiences at a summer camp:

This is me at my first summer camp for young hard of hearing people. We were all on our 20-30's and had a very special summer - I made friends for life! Two years before I went to my first IFHOHYP event and I found out that the community of young hard of hearing is even greater when you meet across borders. Now 5 years later as President of

IFHOHYP, I'm part of the planning team of an international Summer Camp in Denmark - exactly 20 years after the first IFHOHYP Summer Camp was held at the same spot in Denmark - the circle is completed. I'm very proud to be a part of this work together with the IFHOHYP board, the Summer Camp planning team and our main partners; The Danish Association of Hard of Hearing and the beautiful center of Castberggård, where it all takes place. I hope to see a lot of my old and new friends from all over the world in August and to show you my beautiful country.

Questions? Email summercamp2016@ifhohyp.org

See you there!!!

Cheers,

The IFHOHYP Board and Summer Camp 2016 Team



IFHOH President's Message

The date is almost here – June 21st when the International Federation of Hard of Hearing People will hold its 2016 Biennial General Meeting in Washington, D.C., USA, following by our 10th Congress hosted by Hearing Loss Association of America from June 22nd to 25th.

Two important motions will be considered by members at the BGM. One of them focuses on the Convention on the Rights of Persons with Disabilities (CRPD), calling for the Committee of the CRPD to include a member with expertise on hard of hearing issues. This expertise is particularly important in reviewing reports from member states with a lens specific to our community.

The second motion will deal with the important topic of hearing aids and emerging technologies. The motion follows upon the Essen Declaration adopted in 2015 by EFHOH and IFHOH as well as members, to reiterate the importance of affordable quality hearing aids. The motion being considered in Washington DC affirms the need to retain telecoil technology in hearing aids in the face of new developments which are unproven to provide the same benefits for hard of hearing persons. We welcome new developments when they provide improved access for hard of hearing persons.

Our BGM will deal with other issues, including establishing the location for our next BGM and Congress and reporting on activities of the last two years as well as presenting an action plan for the future. I also look forward to the opportunity to connect with members in person; for those unable to attend we will endeavor to keep you informed and I invite you to share your views by messaging me at the email address below.

With best regards,

Ruth Warick
IFHOH President
Email: president@ifhoh.org



A French Initiative: The Best Subtitled Film Award

The majority of foreign films are generally dubbed when screened in France, but some cinemas show the original version with subtitles (VOST), which film aficionados actually prefer. Until recently, this was the only possibility for deaf and hard-of-hearing people to see new films.

But what about French films in France? The situation is slowly improving, as roughly one out of three films are now subtitled for hard-of-hearing people – but unfortunately, their circulation remains extremely limited.

This is why ARDDS (Association pour la réadaptation et la défense des devenus sourds) has launched an initiative to present the “Best Subtitled Film” of the year (Prix du meilleur film sous-titré). This award was conceived with the hope of creating awareness among citizens, the media, professionals, and politicians so that they can fully understand that deaf and hard-of-hearing people have special needs and that these needs can easily be met: films just have to be subtitled for them.

The 2015 award was awarded to Jean-Pierre Améris for *Marie Heurtin*: a true story of a young girl who was both deaf and blind. This film was subtitled in all cinemas and at each showing. He received his award at Cannes last January (see picture).

This initiative is backed by French film director Paul Vecchiali (his 50th film, *Le cancer*, starring Catherine Deneuve and others, has been officially selected by the 69th Festival de Cannes) and supported by a number of organisations, including Bucodes SurdiFrance, Agir pour l'audition, and EFHOH. For practical reasons, it is presently limited to French-speaking films screened in France.

Although the situation and difficulties differ from country to country, the screening of films subtitled for deaf or hard-of-hearing people in cinemas are an issue in many, if not all European countries (as far as I know, Ireland, Belgium, and the Netherlands certainly feel involved). Wouldn't it be nice to join our efforts and develop similar approaches in more countries, speaking other languages, to promote accessibility for hearing-impaired citizens, everywhere?

We would also appreciate receiving feedback from national associations on this situation in their respective countries: to what extent are films screened in cinemas subtitled for deaf or hard-of-hearing people?

You will find up-to-date information on our dedicated website: <http://vfst.ardds.org>

Additionally, you can also view it “machine-translated”: http://translate.googleusercontent.com/translate_c?tl=en&u=http://vfst.ardds.org





4th IFHOH - International **Hearing Loops** and **Accessibility Conference** from 6th to 8th October 2017 in Berlin, Germany

Dear EFHOH Members:

In collaboration with IFHOH – the International Federation of Hard of Hearing People – the German association Deutscher Schwerhörigenbund (DSB) is pleased to invite you to Berlin in October 2017.

Four years after the last Conference in Eastbourne, England, DSB will carry out the 4th International Hearing Loops and Hearing Accessibility Conference. We look forward to see you from 6th to 8th October 2017 in Berlin.

The important conference will be a showcase of the latest technological developments benefitting hard of hearing and deafened persons worldwide. Participants are expected to come from around the globe for the event.

International experts in the role of speakers will give presentations on innovations and advances in technology and tools and about 15 exhibitors will provide you with plenty information on technology, hearing aids, Cochlear implants and individual equipment as well as hearing loop systems (survey, registration, service and maintenance). Last but not least technical innovation (e.g. iOS connection, WLAN, Bluetooth) with its benefit or disadvantage will be prospected and discussed. It is our intension to bring you in close contact to experts and increase your knowledge

about how to settle your hearing loss as well as ever possible.

You surely will enjoy Berlin, the Capital of Germany. It is not only a metropolis with about 4.3 Mio inhabitants, here you will meet living history, e.g. at Brandenburger Tor, where European 's East and West was reunited 25 years ago. Berlin is a cultural center with a full spectrum of theatres and museums. Berlin is reactive, 25 minutes from the Center Potsdamer Platz you can relax on one of the pure waterbodies of Berlin. And Berlin is lively: Urban districts such as Prenzlauer Berg with numerous cafes, a restaurant scene, shopping facilities entertainment and pulsating nightlife are waiting for you. Wouldn't you like to stay here a few days more?

In Best Western Plus – Hotel Steglitz International you will reside comfortable. The hotel is close to transport; you will find bars and restaurants in the hotel and a shopping center within walking distance. The IFHOH Loop Conference will happen there.

We are looking forward to welcome you in 2017.

Renate Welter
Vice-President of DSB

New EFHOH **interim** treasurer

The EFHOH board hereby informs you that Richard Darbéra withdrew from his position as EFHOH treasurer at the AGM in Paris last weekend.

We are happy to have Ritva-Liisa Schäding from Germany with us as our interim treasurer. Ritva-Liisa has previously been EFHOH treasurer and therefore knows the job very well.

Below you see the names of all 5 EFHOH board members and our e-mail addresses.

President:	Marcel Bobeldijk	Holland
Vice President:	Lidia Smolarek Best	England
Interim Treasurer:	Ritva-Liisa Schäding	Germany
General secretary:	Aida Regel Poulsen	Denmark
Board member:	Juha Hietala	Finland

Kind regards,

Aida Regel Poulsen, secretary@efhoh.org



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 subtitling 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


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By journalist Kirsten Winding, Fotos Alex Tran
Translation: EFHOH Secretary, Aida Regel Poulsen

Sigurd has chosen quite an ordinary continuation school, where he participates in everything equally with all the other 119 students. This is a great challenge for him, but it works out better than first expected.

**IT IS COOL, WHEN
PEOPLE FORGET, I
DO NOT HEAR WELL!**

To choose an ordinary continuation school despite hearing loss:

It is Tuesday noon at Faaborgegnens Continuation School <http://faae.dk>. The 17 year old Sigurd Vedsted Drejer collects the plates after lunch, the level of noise is loud and there is conversation everywhere.

Then it is time for to day's messages and those who have something to report, are each given a small microphone in turn to use. The sound from the microphone is transmitted directly into the ear of Sigurd, but that is also the only specific extra thing that is done to facilitate his participation just like all the other students.

- This is the hardest place for me to discriminate all the different sounds from each other. It can be quite overwhelming, he explains and points out in the big dining room, where the ceiling has been led up to the ridge.

This microphone system is also used in the kind of lessons, where communication is in plenum. Otherwise he manages with his Cochlear Implant on his right ear and a hearing aid on the left.

- From the beginning my ambition was to be able to communicate with everybody here. And I have in fact succeeded, I have gained a lot of new friends, Sigurd explains.

It is a conscious choice on his part, that he did not choose one of the continuation schools specially organized and equipped for students with hearing loss. Faaborgegnens Continuation School was previously an Elderly People's home and so the buildings facilitate accessibility physically and acoustically. But it was not till Sigurd applied, that the school applied and was granted assistive listening systems.

- We pride to be adaptable for change and to be able to include a student like Sigurd, head of school, Michael Thagaard, explains.

Into practice

Before the admission Sigurd's hearing consultant from Center for Hearing Loss, Aida Regel Poulsen, had visited the school and checked out, this was a place where Sigurd would be able to work and develop with his hearing loss. And Sigurd was happy, when the school got the seal of approval.

- It is important for me, that I get as much out in 'real life' as possible. I needed new challenges and to meet new people and get new inspiration, he explains.

- There is no hint wrong with for example Frijsenborg Continuation School <http://fus.dk> (where each year they admit about 20 students with hearing loss. Red) he adds. But most likely I would meet many that I already know from connections and associations for young people with hearing loss. At Faaborgegnens Continuation School a whole new world opens up for me, he adds.

Sigurd was born with a hearing loss at 75-90 dB on both ears and went to both kindergarden and school with children with typical hearing, and so he is used to it this way. In the kindergarden he managed with hearing aids and sign language. And at the Svindinge Free school in Nyborg he managed amongst the total of 100 pupils with his hearing aids, until he had his CI on his right ear in 2012.

- I've never really been left out or been bullied because of my hearing loss. But people have made fun of it in a positive way. For example in situations where I have misunderstood something completely or when I have not responded adequately to something funny, he says.

This way Sigurd has always appeared a well functioning Hard of Hearing person. He has had good support from his parents and teachers as well as pedagogues and speech and hearing therapist. And then he has been good at handling his own situation with personal resources and a good sense of humour.



Sigurd is doing well academically in class as well as in group work. Here he works on a presentation with his good friend, Katrine.

- All the time I have always done well in face to face situations and in smaller groups but the situation is never optimal for me in large groups. And to stand up in large groups and say something or do a presentation was not really me, he says.

Therefore it was a bit of a baptism of fire for Sigurd, when Aida asked him to join her at a conference on adolescence with disabilities in Brussels in December. There he sat in a panel next to her an entire afternoon in the big room full of researchers from all over the World. There was captioning available, and last speaker was Sigurd.

- I did a presentation in English about my situation and I received great applause. - That was really great, he proudly admits.

Wishes to manage everywhere

At the continuation school Sigurd continues working on doing presentation in larger groups. - I must be able to manage that. It is a challenge to me, but I'll get there eventually, he says.

Academically the continuation school offers new possibilities for Sigurd. He started at the lowest level for 10th grade to be absolutely sure he was not left behind. But quickly he upgraded to highest level, 10+, where they work projectoriented.

- I wish to apply to the STX in Nyborg (A-levels, red) next year and might as well get used to a high academic level, says Sigurd, who is now doing very well academically.

Socially there are also interesting new things for Sigurd at the continuation school. He shares a room with Niels who has no disabilities at all, and the two of them have become really good friends.

- it is actually only during the nights, when I take off my hearing aid and CI, that he is not able to suddenly say something to me and then he is reminded about my hearing loss, Sigurd explains while he smiles.

He has not yet been among the lucky ones who had his name put up on the schools 'wall of love'. - unfortunately not yet, he says.

A completely unexpected situation occurred, when the school went on a week's trip to Berlin in February. Sigurd had looked very much forward to this tour, but right when the bus arrived in Berlin, a part of Sigurd's CI went broken. - This made me very unhappy. There was no way I could enjoy this tour as I had expected, neither about the sights and events we were going to, nor socially. I do not do very well with just my hearing aid, he says.

They did not succeed in getting the broken part of his CI replaced while in Berlin, but it was there ready and waiting for Sigurd, when he returned home. - This really taught me



Niels, Sigurd's room mate, has no disability. And the two of them soon became very good friends

to remember to fully prepare almost to the extreme that a thing like this should not happen to me again. It was really hard on me, Sigurd admits.

Now it is time for group work. Sigurd finds his place in the group room next to his friend, Katrine, and the two of them immerse into a presentation, Sigurd is to do on the impact of globalization on World Culture. When we ask her, if she finds any problems in cooperating with someone with a hearing loss, she looks astonished and responds immediately: -No. One complete forgets about it!

This is precisely the answer Sigurd likes to hear. His goal is so much to come into practise and manage in line with his peers. Maybe he will become a speech and hearing therapist. Maybe something completely different. Time will show.

This article was published in Danish Association of Hard of Hearing member's magazine: HØRELSEN NR. 03, June 2016.

Other continuation schools also have the possibility to apply for a hearing consultant assisting when admitting students with hearing loss. The consultancy can be applied for from Center for Hearing Loss in Fredericia or Center for Deaf-Blindness and Hearing Loss in Ålborg. This performance is not tariff funded, the consultant will show up when the school applies for it and it is approved by the pupils speech and hearing therapist. The two centres also offer courses for teachers who are to teach and include pupils with hearing loss. See more at www.cfh.dk



EDF's Annual General Assembly 2016 in Dublin

The European Disability Forum's Annual General Assembly and conference was held in Dublin, Ireland on May 21–22. At the opening, EDF's president Yannis Vardakastanis recalled events twenty years ago when negotiations for the UN Convention started. Senator and Chief Executive Officer of Disability Federation Ireland, John Dolan highlighted the EU's great and positive effect on the lives of disabled people. Minister Finian McGrath stated that the ratification of the CRPD has not automatically changed legislation and there is still a lot of work to do.

Conference on legal capacity

The European Conference on legal capacity focused especially on CRPD's article 12 which states that persons with disabilities should enjoy legal capacity on an equal basis with others in all aspects of life.

Claire Hendrick from Inclusion Ireland talked about living with an intellectual disability and shared her horrible experiences on guardianship: she couldn't access money in a bank account and thus had to stay for a while at a homeless shelter. Roisin de Burca from Down Syndrome Ireland spoke about challenges on taking responsibility and her needs for support in different areas of life.

Professor Gerard Quinn of the University of Ireland in Galway argued that all rights are fundamentally the measurements of what it is to be a human. National legal reforms on legal capacity in Ireland, Lithuania and Slovakia were presented at the conference.

General Assembly

The meeting started with discussion regarding EDF's work plan for 2017. Deafblind issues from the Treaty of Marrakech (which focuses f. ex. on creation of accessible versions of books), Design for all –approach and views of survivors of psychiatry will be taken into consideration in a new version of the work plan. Comments were also given for the European Commission's work plan for the year 2017.

Generally, more concrete actions and evaluations were asked for.

There has been a lot of debate about the Accessibility Act among disability organizations. EDF mentioned that the scope of the act is generally limited and two essential things missing from the act are built environment and a proper evaluation/surveillance mechanism. In discussion it was revealed that many business actors are doing their best to water the act down. President Vardakastanis suggested that a working group should be formed to map the essential issues about the act and later, a model letter would be sent for help lobbying at the national level.

The European Pillar of Social Rights is the European Commission's effort to build a framework for employment and social policies. EFHOH's president Marcel Bobeldijk commented on EDF's response to the commission: access to workplaces and distant work options should be taken into account more clearly. In addition to that, when considering life-time learning, the elderly should also have access to interpreting services.

Most European countries have ratified the CRPD. At the present, countries such as Ireland and Iceland have not yet ratified. The ratification of the CRPD has not meant only positive development in European countries. For example, the rights of people with psychosocial disabilities are currently receding in some countries. Members of the audience requested concrete help from the EDF whose response was that EDF supports its members but does not directly involve itself in national politics.

EDF will celebrate its 20 year anniversary in 2017.

Written by Juha Hietala.



These photos are snapshots from the beginning of the seminar: Oskar and Petter, Swedish STTI; Jonatan, compere for the day; Linda from ALDA and Aida, secretary of EFHOH doing their presentations.

VDNR seminar at the Disability House in Denmark

It was with great enthusiasm I went to Copenhagen on May 21st.

VDNR had their seminar. I was invited as one of the speakers and would be able to also hear the other speakers at this event.

Trine Lindhart Gaarsdahl and Jonatan Fruensgaard Andersen had done a very nice job setting up an interesting program for the VDNR seminar.

VDNR is short for Vuxendövas Nordiska Råd, which means Late Deafened Nordic Association.

The number of late deafened people comes down to 1-2 % in the Hard of Hearing population. It is therefore necessary with cooperation across borders to share knowledge and experience. The Scandinavian countries have a long history of cooperating on different matters – also when it comes to hearing loss.

The program of speakers had to be altered in the very last minute, and we were lucky to have Linda Drattell from ALDA, who gave us an overview on how things are organized in California and stressed the importance of sharing the fun with one another.

This also showed – again – the importance of working across borders.

Linda's presentation was nicely illustrated by photos, Liisa Sammelpenger, Finland, could show from her visit in California.

It was very clear, that the barriers late deafened people meet are very similar from one country to another. Still sharing experience on how to solve different problems and also to make UN CRPD work for late deafened people is of great importance.

There was a clearly expressed wish at the seminar to make the work group for late deafened under EFHOH more active. EFHOH board will discuss how to find representatives for each of the EFHOH members associations for a late deafened group.

VDNR had also had contacts from other countries asking to have the seminar streamed to be able to follow when not able to make the journey to Denmark.

There are still things to work on as to:

- Quality of streaming – picture and sound
- Challenges with the STT and SL interpreters
- Choice of language for presentations – in order to streaming
- And many more things..

This is a media we will see more and more in use and therefore we should be skilled to set it up with best of quality to make us stay connected.

It was a very interesting seminar with an audience very knowing and enthusiastic, full of many good ideas and a good sense of humour.

Aida Regel Poulsen



By Louise Carroll, IFHOH Board Member-At-Large with Human Rights responsibilities

IFHOH Human Rights Report

IFHOH UN CRPD Washington Workshop Update

IFHOH member organisations have nominated people from Australia, Bangladesh, Belgium, Cambodia, Denmark, EFHOH, Estonia, Ethiopia, Finland, Germany, Hungary, IFHOH, Ireland, Israel, Japan, Mongolia, Nepal, Netherlands, New Zealand, Norway, Pakistan, Poland, Slovenia, Turkey and Uganda to attend the IFHOH CRPD Workshops to date and all have completed it.

From these IFHOH CRPD workshops, an IFHOH global network of advocates has been developed, all of whom are now able to support people with hearing loss to use the UN Convention on the Rights of People with Disabilities.

In addition, people from organisations in Canada, United States, Vietnam and IFHOHYP will be attending the Oticon Foundation funded IFHOH CRPD workshop in Washington which I am looking forward to facilitating on Tuesday June 21, 2016.

What: IFHOH Human Rights CRPD Global Advocacy Network

Who: Network Facilitator: Louise Carroll
Email: humanrights@ifhoh.org

It was a big undertaking to do this global CRPD workshop project and now that we are nearing the end I would like to offer special thanks to EFHOH President Mr. Marcel Bobeldijk and IFHOH President Dr. Ruth Warick as both gave freely of their time and expertise which hugely benefitted this project - my sincere thanks to you both.

I look forward to seeing EFHOH members who will be attending the IFHOH BGM and the HLAA IFHOH conference in Washington next month.

All the best



Juha Hietala - **New member** of the **EFHOH Board**

To my surprise, I was chosen as a new board member at the Paris AGM in April. Since that time there have been many new things to learn – especially about European disability policy.

I was born in 1976 in a small village in northern Finland. I have been hard of hearing since early childhood. Due to this, I have personal experience in studying and working with a hearing loss as well as experience with using different aids and interpreting services. I graduated from the University of Tampere in 2002 with a major in social policy.

My interest in accessibility and human rights issues are a result of living as a HOH person: I have faced many problems myself. When I was younger meeting other HOH young people helped me to overcome many challenges. Empowerment with other HOH is, in my opinion, one of the most important activities that our membership organizations have to offer.

I have worked in the FFHOH the last eleven years and that has given me quite a strong view on hearing related issues. Since the year 2013, my title has been chief communications officer and my work has included campaign plan-

ning as well as publishing our magazine. My first task for FFHOH in 2005 was to conduct a study concerning elderly people and hearing related services. After that, I coordinated a work-life orientated project where special focus was on accessible working-environments. I have also been a member of FFHOH for over twenty years.

My career on the EFHOH board got a quick start straight after election: I participated in EDF's Assembly in Dublin in May. Together with EFHOH's volunteer Bryan Bong, we have shared ideas on how to renew EFHOH's website. In June I will attend the international IFHOH Congress in Washington D.C.

My favorite hobby is playing guitar. I have practiced playing for about 30 years and I currently have five different guitars. Additionally, I read books and do some weight-lifting.

Please feel free to contact me if you have any questions or comments.



"Early intervention: the key to better hearing care" - **report** from **HEAL 2016**

I had the pleasure to attend HEAL2016, Hearing Across the Lifespan Conference as the speaker and delegate for EFHOH in Cernobbio (Lake Como) Italy, with this year's theme "Early intervention: the key to better hearing care". <http://www.heal2016.org/>

It was an another opportunity to promote EFHOH and network with delegates representing public health, researchers, educators, doctors and audiologists.

Early intervention needs to be followed up by quality of hearing care and support, this is why we decided to present the results of EFHOH survey related to European Standard on services offered by hearing aids professionals. The survey related to possible review of the standard and the need to know our members views. All members have received the results after our AGM in Paris. Additionally I spoke about managing person's expectations, quality of support and rehabilitation. The delegates received an insight at EFHOH cooperation with AEA <http://www.aea-audio.org/portal/index.php/aea-the-association> and EHIMA <http://www.ehima.com/ehima2/> mainly working on Hearing Awareness at the European Parliament, Essen Declaration. I urged them to form partnerships at national level making sure that hard of hearing associations are closely involved in work on access to hearing aids and quality of hearing care. In a nutshell, I urged them not to talk about us without us.

The presentation was well received with delegates engaging in Q&A but also following up later in the corridors. It

makes our work at EFHOH and also member's engagement worthwhile when delegates at such an important forum find time to discuss issues raised further!

A few major themes emerged at the conference ; improving quality of life , research on connecting issues between hearing loss and dementia, early intervention in both cochlear implants and hearing aids uptake, and lastly new technology. However the emerging trend from research showed that quality of hearing care provided by audiologists and hearing care professionals is still important to ensure better satisfaction and right support for persons experiencing hearing loss. Many presentations pointed to the need for resources for rehabilitation and also use of assistive devices. It was encouraging to see it.

EFHOH presence at the HEAL would not be possible without generous support from Amplifon.

Reporting from Cernobbio, Italy
Lidia Best Vice – President

AGREEMENT ON THE WEB ACCESSIBILITY DIRECTIVE

EDF welcomes the agreement reached last night among the EU institutions (Parliament, Council and Commission) on the proposed Directive on web accessibility. It is a crucial milestone to achieve an inclusive digital society, in which 80 million persons with disabilities will be able to participate on equal basis with others. Public websites and apps should no longer exclude anyone.

14 March 2016 | Based on the article of MEP Dita Charanzová, Parliament's rapporteur of the web accessibility Directive, and the Commission's press release, EDF is delighted to announce that the main demands and expectations of the disability movement for this crucial piece of legislation have been listened to and taken on board. Once the final text is made public, we hope for a swift approval from the Parliament and Council, and a rapid and effective transposition and implementation at national level.

This legislation is a great achievement for persons with disabilities: all public sector bodies' websites and mobile applications (apps) will be made accessible, including the electronic documents and multimedia. In cases when they are not made accessible, public websites will need to explain why, in a mandatory accessibility statement. Citizens will have a mechanism to request the content they could not access. Regular monitoring and reporting by Member States have also been agreed, which is indispensable for the success of this legislation.

During more than three years of advocacy work, EDF in collaboration with its members, as well as other civil society organisations and partners, have pushed hard for improving the original Commission's proposal presented in December 2012, which only included 12 public services on websites and very soft enforcement measures. Thanks to the collaboration with the Parliament and the Council, a truly future proof and meaningful Directive can be approved in the coming months, making a real change for persons with disabilities.

Yannis Vardakastanis, President of EDF: "Accessibility is a Human Rights issue. It is a condition for participation in society, for education, for employment, and for access to public services. This Directive is an important step in promoting the rights of persons with disabilities within the EU. The EU, and all EU members states should make all of their public services accessible, including those delivered through the web, including through apps. This Directive provides for a harmonised way to do this within the EU, and will assist the EU, and its member states in meeting their obligations under the UN Convention on the Rights of Persons with Disabilities".

Unfortunately some exemptions will remain in the Directive, such as public broadcasters' websites and live audio-visual streaming, and therefore EDF will need to continue working with its national members for a correct transposition at national level. Additionally, we will need to ensure



that relevant and complementary EU legislation, such as the European Accessibility Act and the revision of the Audiovisual Media Service Directive will properly address what is not covered by the Web Accessibility Directive. Check out EDF's campaign for web accessibility

Contact EDF: Alejandro Moledo | New Technologies and Innovation officer | alejandro.moledo@edf-feph.org

NEW EDF REPORT IS OUT IN SEVERAL ACCESSIBLE FORMATS

2014 and 2015 have been historic years for EDF and 80 million persons with disabilities in Europe. What has the disability movement achieved in these years?

EDF new report explains our actions concerning the UN Convention on the Rights of Persons with Disabilities, non-discrimination, freedom of movement, transport, accessibility, economic crisis, EU funds, and others. The report is available in several formats:

- Accessible PDF
- Accessible Word / Text only
- Easy-To-Read
- Audio
- Sign Language (summary)

10 YEARS OF AIR PASSENGERS' RIGHTS FOR PERSONS WITH DISABILITIES

In July 2006, a regulation on air passengers' rights for persons with disabilities (regulation 1107/2006) was adopted, establishing a set of specific rights for passengers with disabilities in the EU. This legislation has facilitated air travel for millions of persons with disabilities in Europe and has given clear guidance to airports on what services should be provided and how. 2016 is the 10th anniversary of the adoption of this important legislation and the disability

movement marked this anniversary with an event at Dublin Airport, Ireland.

ACCESS CITY AWARD 2017

The European Commission and EDF are launching the competition for the 2017 Access City Award: the European award for cities that are accessible to disabled and older people. EU cities with over 50.000 inhabitants are invited to submit their applications by 8 September 2016 (midnight Brussels time).

EDF AND ORACLE e-ACCESSIBILITY SCHOLARSHIP

Following the success of the first edition, EDF and Oracle offer again a scholarship of 8.000 EUR to a student with disability of a high education programme studying in the field of Information and Communication Technologies (ICT) in the academic year of 2016-2017. Applications are accepted by 15 September 2016.

A NEW STRATEGY FOR PERSONS WITH DISABILITIES

On 17 May 2016, the European Economic and Social Committee (EESC) organised a hearing on "A new strategy for persons with disabilities in Europe". The hearing brought together representative organisations of persons with disabilities, specialised government agencies and EU institutions. EDF and several of its members presented their views on the development of a new strategy to promote, protect and monitor the rights of persons with disabilities in the EU.

OPEN LETTER FOR THE WEB DIRECTIVE

Many thanks for your support so far in the recent work on the open letter initiative for the Web Accessibility Directive. Please download the final PDF version of the letter with logos and signatures, as well as in this public link that you can use in social media: <http://bit.ly/1RRsnux>

The letter highlights the European wide endorsement of the position on web accessibility from a wide range of disability groups. However, as communicated before, Member States are the key objective in this action, as it is the Council the one that is causing the problems for the adoption of this Directive. Therefore, we would like to encourage all EDF national members to endorse and send it to their representatives at national and European level, with a special emphasis in the Ministry in charge of digitalisation or digital affairs.

We would also ask you for sharing it in Social Media. Please download the list of hashtags and people and EU bodies we targeted with our messages on twitter. Please contact Lila if you have any questions on this. (Lila.Sylviti@edf-feph.org). For any other questions, please contact Catherine and Alejandro.

Together we will make this intense effort to make the Web Directive a Directive worth having. It is not acceptable that public sector websites in the EU are not accessible. Soft measures have not been enough. This binding legislation we ask for needs to include all the web and mobile based tools which are used by people to access public services. Let's make sure that decision makers are aware of the importance of this and of their responsibilities

CAMPAIGNING FOR THE INCLUSION OF DISABILITY IN MIGRATION DEBATE AT EU LEVEL

Following two intensive discussions at EDF recent Board meetings, this week EDF and national members have undertaken an advocacy action towards their governments to call for attention to refugees and migrants with disabilities in the EU's approach to the current migration challenge. This week our Greek, Danish and Belgian national councils have co-signed letters to their Prime Ministers, together with EDF. We will keep you informed of further developments, and please let us know if you would like to support this advocacy action.

NEW MEMBERS IN EDF

EDF board welcomed three new associate members: Light for the World, registered in Austria but working internationally, Remploi, from the UK, and Saint Lazarus Foundation, from Malta but also active internationally.

Contact: loredana.dicsi@edf-feph.org

DO YOU KNOW ANY CELEBRITIES WITH DISABILITIES?

In the context of planning for this year's European Day of Persons with Disabilities, EDF is compiling a list of famous Europeans that have disabilities themselves and that could be contacted to support campaigns or endorse our actions. Can you think of any famous artists, politicians, journalists, business people, athletes, activists or other "celebrities"? Ideally, they should be known to an EU-wide audience but we would also like to have persons from as many different Member States as possible, representing a wide variety of disabilities.

Send us your ideas! Contact: marie.denninghaus@edf-feph.org

EUCAN 2016 DESTINATIONS FOR ALL CALL FOR CASE STUDIES

EDF's Full Member from Luxemburg Info Handicap is involved in the EuCAN project. EuCan would like to revise what accessible tourism is and concrete cases would be the best illustration.

Do not hesitate to learn more about EuCAN and send your case as indicated in the article with information.

Contact: silvio.sagramola@iha.lu

EDF MEMBERS PUBLISHED THEIR POSITION ON THE EUROPEAN DISABILITY STRATEGY

Some of EDF members have also published their position on the European Disability Strategy. The International Federation for Spina Bifida and Hydrocephalus have published their position, learn more about their position from the website of If and read their position paper.

Inclusion Europe have also published it. Learn more about their position from the website of Inclusion Europe and read their position paper. Did you publish your own position on a consultation and you would like to share with EDF's members? Do not hesitate to notify EDF.

Contact: loredana.dicsi@edf-feph.org

CRPD COMMITTEE ADOPTS LIST OF ISSUES AND CONCLUDING OBSERVATIONS

The CRPD Committee closed its 15th session last week in Geneva and published the Concluding Observations for Portugal, Slovakia, Serbia, Lithuania, and the List of Issues for Italy.

It also held a day of general discussion on Article 19 CRPD - the right to live independently and be included in the community on 19 April. EDF submitted in advance a written contribution. All written contributions can be found at the Committee's day of general discussion webpage.

All public meetings of the Committee including the State party reviews and day of general discussion were webcast live and have been archived where they are now available for subsequent viewing.

The 16th session will be held from 15 August-2 September 2016 during which the Committee will review Italy, whose rapporteur is Diane Kingston. The 6th pre-session will take place from 5-9 September 2016 during which the Committee will adopt lists of issues on Bosnia and Herzegovina, and Cyprus. For more information, please contact: Ansofie. leenknecht@edf-feph.org

THE COMMISSION REPLIES ON THE INCLUSION OF PUPILS WITH DISABILITIES IN THE EUROPEAN SCHOOLS

As a follow up to the Concluding Observations of the CRPD Committee to the EU, the European Ombudsman wrote to Commissioner Kristalina Georgieva. The European

Ombudsman asked the European Commission to stop rejecting children with disabilities from the European Schools and to provide the necessary support in order for all children with disabilities to be able to participate in the European schools.

The Commissioner replied that the system of the European schools cannot be compared to the national school system and that the obligations to set up an inclusive education as the CRPD prescribes cannot equally be applied to the EU. However, they replied that the 'integration of students with special education needs' is of great important to them and that they have started discussing ways to implement the CRPD Committee's recommendations.

You can read the letter and the reply of the Commissioner on the website of the European Ombudsman.

For more information, please contact: Ansofie. leenknecht@edf-feph.org

"ALL YOUTH IN" WANTS AN ACTIVE AND PARTICIPATIVE YOUTH

All Youth is a Strategic Partnership Project under the Erasmus+ Programme of the European Commission action 2.

The partners of this project are:

- The National Confederation of Disabled People (NCDP), EDF member
- Centre for Equal Rights Inclusion and Development (CERID), the applicant of this project from Romania
- ARDOR an NGO from Romanian
- The European Disability Forum (EDF)

All the organisations partnering are working with persons with disabilities and the Romanian partners are experts in youth projects.

The project aims to increase the youth participation in decision making processes through a platform that will bring all young people with disabilities together by providing online debates and trainings on how to advocate.

This project will help to implement the Youth Committee working plan by creating a platform for young people with disabilities.

The project was submitted by CERID one of the Romanian NGO and if accepted, will last for three years. EDF expects an answer from the Romanian Agency, in charge of implementing the Erasmus Programme in Romania, in August.

Contact: loredana.dicsi@edf-feph.org

EFHOH MEETINGS 2016 & 2017

2016	2016	2016	2016
2-3 July	Athens	EDF Women's Committee meeting	Lidia
6-7 July	Geneva	WHO Stakeholders meeting	Lidia
26-28 August	Berlin	European Conference of Speech to Text (ECOS)	Marcel
23-24 September	Bad Arolsen Germany	30 years DTL	Marcel
26 September	Brussels	Event organised by Ear Foundation	Lidia
28 September	Brussels	EUD conference Sign Language	Marcel
14-15 October	Dublin	EFHOH board meeting	EFHOH board
25 October	Copenhagen	Hear It AGM 2016	Aïda & Marcel
26 October	Brussels	Platform meeting	Marcel and Lidia
12-13 November	Bratislava	EDF Board meeting and Conference	Marcel
29-30 November	Brussels	European Day of Disabled People	Aida and Marcel
2017	2017	2017	2017
20-22 April	Finland	EURO-CIU AGM	Juha
5-6 May	Dublin / Ireland	EFHOH AGM	All board members
6-8 October	Berlin / Germany	IFHOH Loops Conference	All board members

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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.