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# Introduction

More than 2 years ago Marcel Bobeldijk came to me with the idea to write a book about the history of EFHOH. My first reaction was: 'You are crazy!' Marcel suggested sending out a questionnaire to (former) members of the board. We started to make such a questionnaire and sent it out. In the beginning it was difficult to find people who were willing to answer the questions. We also decided to publish these articles in EFHOH journal.

On the other hand it was also difficult to find the data of all board meetings, AGM's, names of board members and congresses. The archives of IFHOH and the FOSS ( Dutch Organisation of Parents of Hard of Hearing Children) were very interesting

Special thanks to Lilian Ebadi Lindqvist, Arend Verschoor and Janny Spronk!

We hope this paper gives you a good impression of what EFHOH has been working for since 1990!

**Thanks to all contributors!**

*Kees Twilt and Marcel Bobeldijk*

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## A Reflection of 20 years of the EFHOH

*Marcel Bobeldijk*

It is a great pleasure for me as EFHOH president to introduce you to the History of EFHOH. I would like to thank all of those who have contributed to this historical book, friends of the hard of hearing movement and former EFHOH board members. In their comments and articles they offer valuable insights into the history and opinions on how our work for the last 20 years of EFHOH was.

For the last 20 years we have worked hard on building up EFHOH from IFHOH-Europe up to EFHOH as an adult organisation, which is at this moment the only European NGO for all hard of hearing people in Europe. European Hard of Hearing people are committed to the European Union's goals. The European Union should now show its commitment to Europeans with disabilities, by working towards a more inclusive and accessible Europe.

Why EFHOH Book? A few years ago our vice president Siegfried Karg left the EFHOH board. With him a lot of historical background information of EFHOH was lost. At the same time Kees Twilt in the Netherlands was working on the NVVS historical book about 100 years of NVVS.

This combination of factors prompted me to ask Kees to write a book about the history of 20 years of EFHOH, so that we understand better about the process of forming IFHOH-Europe to becoming EFHOH in 2012. The EFHOH historical book gives some basic information, both on the question such as: "where was the EFHOH AGM in 2005", as well as: "who was the first EFHOH president?"

The basics for the historical book are personal articles by the different (former) board members and other EFHOH friends, with their personal experiences in the EFHOH Newsletter in the last two years.

Kees and I also hope that this new historical EFHOH document will follow EFHOH activities in the years to come, and we also hope that we can show you an updated version at the next world congress in 2016 or at one of the other EFHOH events.

In the next book we will explore the question: what does future imply at the moment? I think that EFHOH has the opportunity to grow in all aspects, and that she has formed a very good foundation in the last 20 years for a great future in the European disability movement. EFHOH has a lot of opportunities to advocate and lobby for the 81 million hard of hearing people across Europe.

The work of EFHOH at the European Union level is very important, especially in relation to the European Union Disability Act 2012. It is needed that yesterday, today, tomorrow, next week, next month, next year EFHOH knocks on the respective doors of the European Commission, European Parliament, Disability Intergroup of the European Parliament, European Disability Forum (EDF) with the call: "*Hello, don't forget to make Europe also accessible for hard of hearing people in all aspects of our daily life*".

For all this important work it is important that EFHOH will find more financial possibilities so that EFHOH can start working with its own policy employee present directly in Brussels or near Brussels. This needs more active and bigger financial support from our members, the national organisations for hard of hearing people. Or we, as EFHOH members, must accept that EFHOH with a small board of five volunteers can do only small part of all the work of promoting the interests of hard of hearing people in the European political capital, Brussels.

The new EFHOH strategy 2012-2015 is very good starting point and it is also a good map for a new and successful future for our dear EFHOH. The work of EFHOH will be a great benefit for all European citizens.

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## **Back to the beginnings of EFHOH**

*Marcel Bobeldijk*

Kees and I found old papers about the start of EFHOH, written in the first years Euro-IFHOH in the Foss archive.

*This article is based on the article that Werner Bütikofer and Dick Kleinbussink had made.*

Maybe some of you, who were at the IFHOH General Meeting in Jerusalem on August 9<sup>th</sup> 1992, remember that at this general meeting the European Region of the International Federation of Hard of Hearing and Deafened People started.

In the steering committee between 1990-1992 were ; Jack v.d. Berg, Knut M Ellingsen and Hartwig Eisel . They made it possible that in 1992 we held the first IFHOH-Europe board with: Werner Bütikofer from Switzerland, Mirja-Liisa Rontu from Finland, Hans Maier from Austria and Dick Kleinbussink from Netherlands as Secretary.

It wasn't easy to define Euro-IFHOH, because during that period it wasn't an independent organisation. IFHOH members associations at that time were located in Europe working together and therefore have created a secretariat that handles European matters. It had no separate membership (that came later).

The IFHOH board had the right to accept or reject the Euro-IFHOH guidelines. An attempt to make Euro-IFHOH financially independent, by splitting the European part of the IFHOH income in two equal parts, one for IFHOH and one for Euro-IFHOH, was then made.

What was the reason for setting up a separate region? Most of the members did not see the necessity, which is understandable. IFHOH was born out of worldwide movement of HOH and Deafened people, a feeling of belonging together. Why split this up?

The main reason is an external one. In 1985 IFHOH's former General Secretary, Mrs. Hannelore Hartmann, made the first contacts with the "Bureau of Action in Favour of Disabled People" of the European Commission in Brussels. IFHOH became a member of the "Dialogue Group", with access to the European Commission.

The main purpose was that our special handicap – hearing loss after acquisition of speech – would be recognized as a separate handicap, and not just as a part of the handicap of being deaf. Promoting sign language, deaf culture etc. are important, but IFHOH has a great number of other priorities.

Another aim, to receive European subsidies, had some results but never produced very much.

However, the contacts with "Brussels" did not cost us very much either: IFHOH never had to pay for our numerous participations in the European Commission meetings and conferences.

At the end of the eighties' it looked as though IFHOH would lose its place as a member of the Dialogue Group of NGO's and thereby losing whatever influence and recognition it had. The European Commission's main objections were that; IFHOH was too international and that it had Members in only seven of European Union countries. It is understandable, that the European Commission only wishes to subsidise the expenses of seminars and conferences of handicapped people, who live within the European Union.

The ratification of the Maastricht treaty was also very important for the disabled people in Europe, including the hearing impaired people!

It is remarkable, that the interest for European cooperation between HOH people is strong outside the European Union, but that a number of organisations within the European Union do not seem to feel the need of international contacts. In 1992 there were no IFHOH members in Ireland, Luxembourg, Spain, Portugal and Greece, and the contacts with Denmark and United Kingdom could be better.

What were Euro-IFHOH's plans?

First: streamline the organisation, work on a good set of guidelines and find a way to secure a better financial position. The Jerusalem IFHOH General Meeting in 1992 awarded Euro-IFHOH a budget of 3000 euros for this year and 7000 euro for next year, which was not a lot.

A step towards this goal was to hold a Euro-IFHOH General Meeting in 1993 in Bad Berleburg/Germany. This AGM was run parallel of IBAF's third International Conference "Rehabilitation of the HOH, the Deafened and pre-lingual Deaf people.

Secondly: Convince HOH people and organizations in those other European Union countries, that with a growing European Unity they have to be part of, and strengthen, the European HOH movement.

Thirdly: Many of the former Communist states in the Eastern Europe are looking for contacts and help from the West. This also applies to their HOH and Deaf associations.

Furthermore Euro-IFHOH would be engaged in the same sort of work as its mother organisations IFHOH: establish contacts between HOH associations provide information and organise meetings.

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## **Siegfried Karg**

### ***When did you come in contact with IFHOH / EFHOH for the first time?***

I attended the IFHOH World Congress in Graz, Austria, in 1996, as a delegate of Pro Audito Winterthur, our local Hard of Hearing organization, whose president I had become in 1993. That was my first international meeting.

In the meantime I have attended the congresses in Sydney, Australia, in 2000, in Helsinki, Finland, in 2004 and in Vancouver, Canada, in 2008.

### ***Can you tell us something about yourself and your work on the local and national levels in Switzerland?***

Through my wife's aunt, who was hard of hearing since childhood, I came in contact with the problem of hearing loss for the first time (1971). She could not understand me on the phone with her normal phone, so we got her a special phone with inductive coupling, and from then on she could understand me very well. That was the starting point of my later activity for induction loops.

While I was a pastor in a suburb of Zurich, Switzerland, a new induction loop was installed in the church sanctuary and I wrote my first article in our local church magazine about how to use the loop (1987).

Years later as pastor of the city church in Winterthur, Switzerland, I visited a parishioner, who turned out to be the former president of the hard of hearing organization in Winterthur. Later on I was invited to be a speaker at their meeting. Afterwards I was asked if I would be willing to become the vice president of the Winterthur association, and was then elected in 1992. In 1993 our president passed away unexpectedly and I had to take over the presidency, an office I still hold.

In 2003 I was elected to the central board of Pro Audito Switzerland, of which I also remain a member.

***When did you become vice president of EFHOH and why?***

Because of my activities for hard of hearing people in Switzerland and internationally (especially in Austria and Germany) and because of my fluency in English, the board of Pro Audito Switzerland asked me to be a candidate for the EFHOH board. I was elected as vice president in Ljubljana, Slovenia, in 2002.

***Who was on the board at that time?***

The president at that time was Lillian Vicanek from Norway, general secretary was Seppo Matinvesi from Finland, the treasurer was Marcel Bobeldijk from the Netherlands and Paul Zylberberg from France was board member.

***What have you done within EFHOH?***

I was in charge of the contacts with the German speaking countries (Germany, Austria, and Switzerland) and also with the industry. I looked for new sponsors (successfully recruited two new ones) for IFHOH and EFHOH. I helped the Austrian association (ÖSB) with the organization of the EFHOH annual general meeting in Graz, Austria, in 2003. I also helped with the changes to the IFHOH constitution and translated the final English version passed in Dubrovnik, Croatia, in 2006, into German for the court in Hamburg, where IFHOH is registered.

I was instrumental in obtaining a special grant from Pro Audito Winterthur to finance the part-time secretary for IFHOH and EFHOH (Lilian Ebadi Lindqvist) in Stockholm, Sweden, and drafted the contract between HRF, the Swedish Hard of Hearing organization, and IFHOH and EFHOH.

I was chairman of the organizing committee for Hearing Loops, the first international conference on inductions loops, in Winterthur, Switzerland, in the fall of 2009, which was organized by EFHOH, Pro Audito Switzerland and Pro Audito Winterthur.

***What was for you personally the most important subject/moment/topic during your term in office?***

The first international conference HEARING LOOPS in Winterthur, which people from 15 different countries (including Australia, USA and Kuwait) attended. During the year preceding the conference, all of my free time was taken up organizing this conference.

I am happy about the fact that a second conference will be held in Washington, D.C., USA, from June 18-20, 2011. This follow-up conference will be organized by HLAA (Hearing Loss Association of America) together with the American Academy of Audiology.

***Can you say something about the cooperation among EFHOH, IFHOH and IFHOHYP?***

EFHOH is a regional organization of IFHOH. All three organizations have the same common goal. Therefore in my view the good cooperation during the 8 years I was EFHOH vice president should be continued.

***What was the most sad or difficult moment/topic in your term?***

I wrote to three companies who produce hearing aids and assistive listening devices, asking them to become sponsoring members of IFHOH and EFHOH. One company responded with a negative answer, the two others did not bother to react at all, even after I wrote a second letter to the CEOs.

***What is your opinion about the role / tasks of EFHOH as a European NGO for HOH people?***

Hard of Hearing People are the largest group of persons with a disability in Europe. Unfortunately most people do not realize their specific needs. A majority is under the false impression that people with hearing loss are signing deaf people (who actually constitute only about 1% of people with hearing loss). 99% are hard of hearing people who do not use or understand sign language. They

need induction loops in public buildings and speech to text translators (CART) and not sign language interpreters. This fact should be stressed in the general public, but also within the movement of persons with disabilities.

***Can you tell us something about your experiences in EFHOH?***

During international conferences (World Congresses of the Teachers of the Deaf, in Sydney, Australia, in 2000, and in Maastricht, The Netherlands, in 2005) and, since 2002, at the Annual General Meetings of EFHOH and the Biennial General Meetings of IFHOH, I have talked to a lot of hard of hearing people worldwide and listened to their personal stories. I have heard a lot of sad stories about how people with hearing loss were treated, or sometimes even mistreated in former years. I have also realized that every individual hearing loss is different. These stories have motivated me to be an activist for the rights of hard of hearing people.

***How do you see the future of EFHOH?***

I cannot foresee the future, but in my view EFHOH has to become a more professional organization. A first step has been taken in that IFHOH and EFHOH have a part time secretary and an office in Stockholm to facilitate communication between members and sponsors.

***Congresses like the World Congress in Vancouver and the Hearing Loops International conference are very important. What do you think about their role in the future?***

World Congresses every 4 years are important to foster international cooperation. However, we should be realistic and not plan with 1000 or more participants. Smaller conferences dedicated to specific topics (like the Second International Hearing Loops Conference in Washington D.C., see above) can help to create a barrier-free world for hard of hearing people.

***Why did you decide not to be a candidate for the EFHOH board again?***

I was vice president for 8 years and I want the work to continue with younger people. I am pleased that Lidia Best, who was elected as new board member of the EFHOH board in Stockholm, is 20 years younger than I am.

***What are you going to do in your free time after you have left the EFHOH board?***

I will continue my work as a pastor and chaplain in a nursing home in Winterthur for another year until my retirement. In this capacity I am often called upon to help our residents with their hearing aids. In my free time I am still president of Pro Audio Winterthur and a board member of Pro Audio Switzerland, so my involvement with the community of hard of hearing people will continue. Therefore I am sure I will not have too much spare time on my hands.

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# Induction Loops

*Siegfried Karg*

## **Introduction:**

One of the major goals of EFHOH is to encourage the installation of assistive listening devices, especially induction loops, in public venues with a large distance to the sound source, where there is reverberation and/or background noise. In such situations even the most advanced hearing systems or cochlear implants show their limitations, because the systems would have to break physical laws of room acoustics.

In 2006 EFHOH received a donation from the local Hard of Hearing chapter in Winterthur / Switzerland (Pro Audito Winterthur) as a special gift in honor of their 90<sup>th</sup> anniversary. The donation was supposed to be seed money for organizing an international conference on induction loops.

The EFHOH board suggested having such a conference in conjunction with the Annual General Meeting in Oslo / Norway in 2007. But the Norwegian Hard of Hearing Organization had already made different plans for this conference. Therefore the original idea was postponed.

Then in 2008 Pro Audito Winterthur, together with Pro Audito Switzerland (the Swiss Hard of Hearing Association) suggested having the first Hearing Loops International Conference in Winterthur / Switzerland from September 25 to 27, 2009. The EFHOH general meeting in Dublin / Ireland in 2008 agreed to have this special conference.

## **First Hearing Loops International Conference in Winterthur / Switzerland (2009):**

The venue of the conference was the Zurich University for Applied Sciences at Winterthur near Zurich. About 100 people from different European countries, from Australia, the USA and from Kuwait attended the international conference.

The conference voted on and passed the following resolution with only 2 opposing votes:

**“Hearing Loops**, the first international conference on audio frequency induction loops (AFILS) for people with hearing loss - with participants from Austria, Australia, Croatia, Finland, France, Germany, Italy, Kuwait, Netherlands, Russia, Slovenia, Sweden, Switzerland, United Kingdom, and USA - passed the following resolution at Zurich University of Applied Sciences at Winterthur / Switzerland on September 27, 2009.

**An audio frequency induction loop system (AFILS) is an inexpensive, efficient and universal system to enable people wearing hearing aids or cochlear implants to hear in public situations.**

We recommend that

hearing aid manufacturers, manufacturers of cochlear implants, physicians, audiologists and hearing instrument specialists shall communicate the benefits of hearing aid / cochlear implant telecoil receivers for phone listening and assistive listening and educate people who are hard of hearing accordingly.

venues and service points where sound is broadcast shall offer assistive listening, such as induction loop systems designed to the IEC 60118-4:2006 standard, that broadcast sound directly to hearing aids and cochlear implants, enabling them to serve as customized, wireless loudspeakers (without the need for extra equipment).”

The conference focused on Audio Frequency Induction Loop Systems (also called “Hearing Loops”). In addition, the participants were open to new technologies to be used with AFILS or eventually replacing them. At present no technology is in sight which is as universal, as inexpensive and as effective for people with hearing loss. The conference had its focus on AFILS in public

places and not on personal mobile assistive listening systems where other technologies (e.g. Frequency Modulation FM) can be of real benefit.

The conference language was English with simultaneous translation into German. All the presentations, including the Power Point Presentations, were videotaped and can be downloaded as video streams from the conference website [www.hearingloops.org](http://www.hearingloops.org)

## **2<sup>nd</sup> International Hearing Loop Conference in Washington D.C. (2011):**

Participants from the USA (especially Brenda Battat, CEO of the Hearing Loss Association of America, and Dr. David Myers, "Loop America") who attended the Winterthur conference in 2009 favored the idea of having a follow-up conference in Washington D.C., USA, in 2011 in conjunction with the Annual Convention of the Hearing Loss Association of America (HLAA). The 2<sup>nd</sup> international conference was organized by HLAA together with the American Academy of Audiology (AAA) in the Washington D.C. area from June 18-20, 2011 with presenters from the USA and from Europe.

In my opinion, the following could be considered "results" of the 2<sup>nd</sup> International Hearing Loop Conference:

There is growing awareness of the necessity for the installation of hearing loops in public facilities in the U.S.

There is growing awareness among people with hearing loss that a telecoil in the hearing aid/cochlear implant can be used not only with the telephone, but is also of use in public facilities with hearing loops, especially when the distance to the speaker is big (e.g. lecture halls), and/or there is reverberation (e.g. in houses of worship, high ceilings), and/or there is background noise (e.g. air conditioning systems). People with hearing loss need a much higher so-called signal-to-noise-ratio (SNR) to understand speech, than people with normal hearing do. The hearing loop improves the SNR considerably.

There is growing awareness among audiologists in the U.S. of the need for hearing loops in public facilities. The 2<sup>nd</sup> conference was organized by the Hearing Loss Association of America (HLAA) in conjunction with the American Academy of Audiology (AAA). This is a giant step forward for hearing loops because it is essential that audiologists make their clients aware of the advantages of a telecoil in the hearing aid / cochlear implant. Otherwise, clients might purchase one without a telecoil, therefore rendering them unable to use a hearing aid compatible (HAC) phone, or a hearing loop in a public facility.

There is growing awareness that hearing loops in public facilities have to be installed by professionals, in order to meet the international standard set by the International Electrotechnical Commission in 1981 and revised in 2006. Only such audio frequency induction loops actually give people with hearing loss the speech intelligibility which is technically possible today.

Presentations from different countries at the Washington conference indicated that in Europe, although many hearing loops have been installed, only very few meet the international standard (quality control is lacking).

There is growing awareness that hearing loops newly installed in the U.S. should meet the international standard. It is not primarily a matter of cost; it is a matter of a lack of know-how by installers.

As a consequence, there is growing awareness of the need for professional installers of hearing loops in the U. S., requiring a special certified training program (e.g. together with the American Audio Engineering Society).

There is growing awareness among manufacturers of hearing aids of the importance of telecoils in hearing aids, a technology which has existed for more than 50 years. Greater emphasis should result in improved performance of telecoils.

There is growing awareness among hearing aid manufacturers of the fact that at present induction loop technology is still the only technology that can be used universally, and can be coupled to the telecoil of the individual hearing aids/cochlear implant without requiring an extra assistive device (e.g. FM or infrared receiver with neck loop).

There is growing awareness that consumer organizations of people with hearing loss, hearing aid manufacturers, audiologists, and manufacturers of audio frequency induction loop drivers should work together closely to improve the quality of life of millions of people with hearing loss worldwide.

There is growing awareness that consumer organizations of people with hearing loss should encourage owners of public venues (including houses of worship) to have hearing loops installed in rooms where speech intelligibility is important. Millions of people with hearing loss are consumers, too, and want to be included and not excluded.

Dr. Ruth Warick, Vancouver / Canada, President of the International Federation of Hard of Hearing People (IFHOH), stated in her closing remarks at the 2<sup>nd</sup> International Hearing Loop Conference in Washington D.C.:

**“I think the future is bright.**

**Telecoils and hearing loops used to be the past,  
and now it’s the future.”**

Some videos with captioning of the Washington conference can be downloaded from the website of the Hearing Loss Association of America [www.hearingloss.org](http://www.hearingloss.org) Look under “Get in the Hearing Loop”.

The first Hearing Loops International Conference organized by EFHOH, Pro Audio Switzerland and Pro Audio Winterthur in 2009 was a starting point to further the use of hearing loops. It is the hope that the momentum from the Winterthur and Washington D.C. conferences will be strengthened, for the sake of people with hearing loss not only in Europe but worldwide.

It is the hope that a 3<sup>rd</sup> international conference will follow.

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## Bas Koops



### ***When did you get for the first time in contact with EFHOH?***

I don't know exactly when it was that they asked me to become EFHOH's treasurer. I destroyed all digital data. But I was 2 years with EFHOH when Marcel in 1999 succeeded me as treasurer.

### ***Can you tell something about yourself and your work at local and national level in your country?***

I (hard-of-hearing and tinnitus) joined the NVVS somewhere in 1990 as board member of the local NVVS department "Midden Holland" where I was respectively general board member, treasurer, secretary and president. The department was dismantled some 3 years ago. I was also Secretary of the NVVS Committee Tinnitus & Hyperacusis during some years.

### ***When did you join the board of IFHOH/EFHOH and why? Who were in the board? What have you done within IFHOH/EFHOH?***

I became board member in 1996-1997 other board members were in that time President Christina Wahrolin from Sweden, Secretary Mirja Liisa Rontu from Finland, and Board-members Christopher Shaw from the U.K. and a man from Germany whose name cannot recall. The previous treasurer was Mr. Maier from Austria who I never met.

### ***What is your opinion about the role/tasks of EFHOH as a European NGO for HOH people?***

Hard of hearing has no boundaries. Countries should cooperate, exchange experiences and knowledge, learn from each other in order to achieve common goals, exchange local experiences with respect to support to Hard of Hearing people, information supply, legislation, insurances, developments in hearing aids.

### ***Can you tell something about your experiences in EFHOH?***

There were two main challenges for a treasurer : improving the poor financial administration, and running the financial administration that came with the project "Managing a hard of hearing association", with two seminars, one weekend in Helsinki and one in Stockholm, attended by representatives from EFHOH members of many countries. The project was partly sponsored by a European Committee for the disabled.

### ***Can you tell something about the co-operation between EFHOH with IFHOH and IFHOHYP?***

I cannot remember many exchanges of thoughts between the mutual board members but there must have been. EFHOH's name was IFHOH-Europe in those days, so in fact a sort of sub-division of IFHOH which gave some friction I think. With IFHOHYP I have no experience, but I remember that members did attend our Annual Meetings.

### ***What was for you personally the most important subject/moment/topic in your period?***

Topics were the annual meetings (in Helsinki, Istanbul and Geneva) and most of the entire project.

***What was the most sad or difficult moment/topic in your period?***

Bad surprises were the poor financial administration my predecessor had left behind. The fact that neither the President nor the Secretary were aware of the bad financial situation. My predecessor had left a box with rubbish without any informative value, so that I had to reconstruct the past 2 years, and went away with several thousands of Euros for some vague reason. It took me more than half a year and the help of the EFHOH local bank in Graz to get the money back. Disappointing was also that the European Committee did eventually not compensate the full project costs. Eventually Scandinavian members supplied the deficit. (Nevertheless it was all very challenging,)

***How do you see the future of EFHOH?***

Continue “spreading the word” amongst governments, insurance companies etc. and most of all the hard of hearing people, this is especially challenging in the present times of bad financial prospects.

***Congresses, like Vancouver and the loop system conference are very important. What do you think about their role in future?***

Don't give up!

***What were you going to do in your free time when you had left the IFHOH/EFHOH board?***

Next to EFHOH, I had responsibilities in my local NVVS department which took much time.

I was 70 when I decided to leave the NVVS environment. Our local Department “Midden Holland” was dismantled (like many other departments) , and : I had private backlogs, saving and digitalizing things for my children, like 2.500 slides and about 20 old (holiday) videotapes, and I have to look after my 91 year old blind sister.

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# Lars Linden



## ***When did you get for the first time in contact with EFHOH?***

My first international contact was in Berlin. I guess the Berlin club celebrated its 90<sup>th</sup> anniversary. We initiated a group consisting of Hester Thierens (NL), Chris Shaw, (GB) and myself Lars Lindén (SE) to prepare an international organization of the hard of hearing people. After one year we organized the inaugural meeting of IFHOH in Stockholm 1978. EFHOH was established some years later – under my presidency of IFHOH.

## ***Can you tell something about yourself and your work at local and on national level in your country?***

I have been active within the Swedish hard of hearing organization (HRF) both on national and local level. I used to belong to the national Board of the HRF for more than 25 years. I was the president of the Stockholm club between 1976-1999. Since 2009 I am president of the Stockholm club again.

In IFHOH, I was the first general secretary and the 2<sup>nd</sup> president. I also organized the 2<sup>nd</sup> Congress of IFHOH in Stockholm 1984

## ***When did you join the board of IFHOH/EFHOH and why? Who were in the board? What have you done within IFHOH/EFHOH?***

As above I joined the board at the inaugural meeting 1978 as general secretary. Why? The 1<sup>st</sup> board: Christopher Shaw, President, myself general secretary, Bengt-Åke Leijon (Sweden) Treasurer, Kalle Tervaskari (Finland) vice president (?) and a teacher from Berlin, whose name I forgot.

## ***What is your opinion about the role/tasks of EFHOH as a European NGO for HOH people?***

I think that the EFHOH is a must for the hard of hearing European people. I also think that IFHOH/EFHOH has developed as an organization all the time and is still developing in a good way!

## ***Can you tell something about your experiences in EFHOH?***

My experiences are mainly from the work within the IFHOH. Generally, however, international cooperation is important and difficult. Financing international cooperation is always in every national association in conflict with the national financing.

***What was for you personally the most important subject/moment/topic in your period?***

That was to formulate the organization itself and try to build up a strong economy. Personally the organizing of the Stockholm Congress 1984 was very important.

***What was the most sad or difficult moment/topic in your period?***

During my leadership we didn't reach the goal to be accepted by the UN.

***How do you see the future of EFHOH?***

A strong hard of hearing organization will be of immensely importance in the future to in getting standardized communication systems all over Europe and hopefully all over the world

I believe that the loop systems will be important also in the future but successively the intelligent FM-systems or similar systems will take over as the main technical help for hard of hearing people.

***What were you going to do in your free time when you had left the IFHOH/EFHOH board?***

I concentrated more on my family, employment and friends.

***Any other remarks?***

Sometimes I miss the many friends I got.

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## History of subtitling



*Giuliano and Giacomo Pirelli*

In the modern society television broadcasts play a very important role. The accessibility to information they provide is vital to all citizens, in particular deaf people. Technical solutions such as captioning, which are proposed by television networks, may facilitate that access.

The ancestor of modern movie captioning were *intertitles*, that is captions used as dialogues and as descriptions of sequences in mute movies (early Charlie Chaplin movies). Captioning as such started in the USA in 1948 at cinema. Television captioning started in the US in 1970 when the National Bureau of Standards decided to create a portion of the network signal to send information at a national level. In 1972, in the USA, PBS (Public Broadcasting Service) broadcast the *French Chef* with subtitles embedded in the screen (*open-captioning*).

In 1972 in the UK with the system Ceefax by BBC. In 1979 television subtitling started in the UK for the 1<sup>st</sup> time in Europe with a BBC broadcast: *Quietly in Switzerland*, a documentary about deaf children. In 1986 the television real time captioning arrived in UK. BBC first captioned program was *Blue Peter*, a program for children. The first live captioned events of large importance were *Margaret Thatcher's resignation* and *The Gulf War* in 1990. In 1995 the BBC created a system of live-subtitling with time intervals, the *BBC Live Subtitling System*, where stenographers and subtitlers could work in different programs simultaneously. In 1996 the first live captioned event for the BBC and the European Broadcasting was the Olympic Games of Atlanta by steno-typing.

In 1976 the FCC (Federal Communications Commission) adopted *Line 21 of Vertical Blanking Interval (VBI)*, which would then be used in *closed-captioned* broadcasting. On 16th March 1980 in the US the first regularly *closed-captioned* television serial was broadcast with a specific decoder for the subtitles.

Television captioning arrived in Canada in 1981. In 1982 television real-time captioning started in the US with the Academy Awards, then the Los Angeles Olympic Games in 1984. In 1990 the Federal Communications Commission (FCC) approved the Television Decoder Circuitry Act, requiring that by 1993 all television sets had *decoders* incorporated to visualize captions. In 1994 on Web TV the first captioning of the online video *Information Superhighway Speech* of the USA VP,

by Al Gore. As of 1<sup>st</sup> January 2006, all new programs in English, analogically broadcast after 1998 and/or digitally broadcast after 2002, had to be captioned.

In 1999 the Commission of Ofcom (Office of Communications) decided to extend subtitling requirements to 80% of the air time in all the seven BBC channels. Since 2001 BBC started to try out respeaking to subtitle their broadcasts in real time. This new professional role allowed subtitlers to have more rapid training to produce the subtitles in acceptable quality and in shortest time possible.

In 2003, BBC introduced a new system of live subtitling, K-live. It permitted stenographers and respeakers to work together for the same program.

In October 2007 Alan McGuffog, responsible for Red Bee Media, said at the EBU conference that respeaking covered 60% of BBC television programs. In May 2008 for the first time BBC was very close to reach 100% of captioned broadcasts 2 years after the US.

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## **The VOICE Project**

**Giving a VOICE to the deaf by developing awareness of VOICE to text recognition capabilities**

*Giuliano and Giacomo Pirelli*

The VOICE Project has investigated the use of voice recognition systems in conversations, conferences, television broadcasts and telephone calls. It started in 1996 in the EC Joint Research Centre (JRC) at Ispra and was then sponsored and funded by the EC Directorate General Information Society in 1998-2000. The Project has developed prototypes of user-friendly interfaces allowing for an easier use of commercial products translating voice into screen messages and subtitles for conferences, classes, lectures, TV and theatre shows, and so on. This is a significant help for people with hearing impairments, because it reduces the gap between them and the hearing population. The first applications in Research in Assistive Technologies and their further developments at JRC have achieved excellent results and demonstrated the feasibility of applications of low-cost and high-performance new technologies for all citizens, in a *design for all* approach.

More than one hundred workshops have been organised, where the VOICE Project was presented to more than 6000 users. Its prototype demonstrator has been used for subtitling part of the workshops, as a demonstration of its feasibility and as a validation in the field. The subtitling system has been used in several schools in order to deliver to all the students of a class the same information, by means of the same words, at the same time. In particular some activities for the MOISE, Netdays and NEMO projects have been organised in collaboration with the EC Directorate General XXII (Education).

The VOICE Project has proposed the development of new technologies and new behaviors in the field of speech-to-text recognition and has stimulated and increased the use of new, widely diffused technologies, namely the Internet, in order to tackle the problems that may be encountered by the deaf and the hard-of-hearing. More precisely, the Project was also aimed at uniting, by means of an Internet VOICE Forum, associations, companies, universities, schools, public administrations and anyone else interested in speech recognition. This Forum has contributed to defining technicalities related to the needs of the deaf and the hard-of-hearing in the fields of speech recognition and of TV subtitling. All the phases of the Project saw the active participation of the Associations of people

with hearing impairments. They have been encouraged to comment and suggest at any time. The feedback collected during such discussions has been disseminated through the Internet, along with the results and the examples of good practices in the field, thus anticipating the trend of Social Networks.

In 2001 and 2002 the activities of the Project actively worked on the harmonisation of television subtitling, in collaboration with the European Broadcasting Union and the CENELEC Normalisation Committee, with the support of the EC Directorate General Enterprise. JRC contributed to create the CENELEC TV Broadcasting for All Group and to prepare the Conference TV Broadcasting for All in Seville on June 2003. In the *European Year of People with Disabilities 2003*, several activities aimed at further spreading the achieved results, informing both end users and services providers, thus increasing their awareness. The European Year's closing event was the Conference *eAccessibility by Voice*, held at Ispra (Varese, Italy) in November 2003.

In the following years, the acquired experience helped in broadening the field of application to other technical means and considering also other difficulties in communication, security and safety, encountered by the elderly, the disabled or the disadvantaged. The SESAMONET (SEcure and SAFe MObility NET) Project's objective was the development of an integrated electronic system to increase the mobility of people with visual disabilities and their personal safety and security. Usability and accessibility aspects have also been considered in the PRIMA (Passport, Identity Management and Access Control) Action, carrying out application-oriented research in the area of identity controls and of e-gate automatic systems in airports. The VOICE Project has been a reference within JRC and its coordinator participates in the activities of the InterService Group on Disability, dealing with the EU's wider effort to promote the mainstreaming of disability issues in line with the EU Disability Strategy 2010-2020 and the United Nations Convention on the Rights of Persons with Disabilities.

Different activities have been undertaken in order to spread the use of such applications in different fields of the daily life, like cinema, theatre, leisure time, sports. This one has been particularly considered in view of Turin 2006 Paralympics and 2007 Universiade. In the field of research, the VOICE Project has collaborated with the International Symposiums on Live Subtitling and the on line Master on AudioVisual Translation (METAV). Drawing on the results of the VOICE Project, some activities are still on going in collaboration with some University teachers aimed at the development of the professional figure of the respeaker, who uses speech-to-text technology to produce live subtitles. In this framework, particularly significant is the creation of the International Association on Respeaking (onAIR) aimed at diffusing the use of speech-to-text applications in every aspect of the community daily life, including Web radio subtitling promoted by the OltreSuoni project.

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## Jürgen Schäding



### ***When did you get for the first time in contact with EFHOH?***

ICHOHYP – first in 1969 I heard about an international rally when I join the local hard of Hearing club (BdS e.v. Hamburg, Germany). In 1970 I took part during the International rally in Skarnes, Norway.

The begin of this international youth rallies started 1967 in Denmark (DTJ Lejren, Middelfart, Fünen).

### ***Can you tell something about yourself and your work at local and on national level in your country?***

In Skarnes, Norway, the discussion starts to form an international committee to organize international rallies, meetings and information exchange. One of the important persons was Christopher Shaw (GB), and Kalle Tervaskari (FIN). In Germany the youth organization of the “Deutschen Schwerhörigenbund e.V.” installed the position of international matters (Auslandskorrespondent) in 1971 or 1972.

### ***When did you join the board of IFHOH/EFHOH and why? Who were in the board? What have you done within IFHOH/EFHOH?***

ICHOHYP – The committee was founded in 1973. First chair man was Christopher Shaw, first vice chair man Jürgen Schäding, treasurer David Brown (?), General secretary ? In 1976 Christopher Shaw left the ICHOHYP board and started working to settle the IFHOH. So I became chair man for

the next period. In 1977 (Berlin) there was a meeting of the leaders of national hard of hearing organizations from Europe. The target was to form an international organization for all hard of hearing people. I attend this meeting for ICHOHYP (Here the young people were more flexible and faster than the organizations of the older one). 2 years later IFHOH was founded in Hamburg, Germany (1979).

It was always difficult to get money to run the business of IFHOH (voluntary base). The board tried to get some grants from the EU – but this was not possible because IFHOH is an international organization. To solve this problem they form a new section for EU area: Euro-IFHOH. Later this was renamed to EFHOH with an own location in the Netherlands.

***What is your opinion about the role/tasks of EFHOH as a European NGO for HOH people?***

There must be a non governmental for HOH people to fight for better integration and respecting their specific rights and tasks. If we do not reach this target on an EU base the HOH people in many EU countries will be in a poor position.

***What was for you personally the most important subject/moment/topic in your period?***

From 1973 – 1978 the most important matter were the international rallies as place to meet each other for exchange and learning how things can work and problem could be solved.

***What was the most sad or difficult moment/topic in your period?***

The greatest problem was to get in contact for information exchange (communication). Telephone cost was terrible expensive (and not all could hear at the phone). Fax was not available (just under development). No Personal computers, no translating programs, no internet, just time consuming dictionaries ...). You must use letters – handwritten or type writer – copy the letters and sending them by post (extra costs for stamps)

***How do you see the future of EFHOH?***

EFHOH is the voice of the hard of hearing people in EU. It is part of the social systems of handicapped people and has the possibility of influence to the political area – much better then the national organizations can do it (in several countries they are still too small).

***Congresses, like Vancouver and the loop system conference are very important. What do you think about their role in future?***

The first international congress of the hard of hearing was held in Hamburg from 8<sup>th</sup> – 10<sup>th</sup> August 1980. The program included a wide range of different aspects of hard of hearing matters. The wide range gave a lot of possibilities for the attending people for contacts and information exchange.

From my point of view the congresses should be a place for knowledge exchange, present actual developments and shows missing things to the public and governments (local and national areas). What I am missing is something like a “central place” were all this information’s will be available for anyone. This should be possible with our actual technologies.

***What were you going to do in your free time when you had left the IFHOH/EFHOH board?***

Some small actives in the local hard of hearing club.

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# Werner Bütikofer



***When did you get for the first time in contact with EFHOH?***

A few years before the founding of EFHOH, at the Annual General Meeting of IFHOH and at the congresses of IFHOH.

***Can you tell something about yourself and your work at local and on national level in your country?***

From 1974 till 2001 I was secretary general of the BSSV (full time job). The BSSV was involved in an active way in the founding of both the IFHOH and the EFHOH.

***When did you join the board of IFHOH/EFHOH and why? Who were in the board? What have you done within IFHOH/EFHOH?***

I have never been a member of the IFHOH board. In the EFHOH I was at in the beginning President, together with representatives of Sweden, Finland, Holland and Austria. After two years I changed function with Christina Wahrolin. She was from an EU country, had a hearing problem herself, was in political circles very well known, engaged and a woman. Four good reasons to change roles.

***What is your opinion about the role/tasks of EFHOH as a European NGO for HOH people?***

The EFHOH has the enormously important task to represent the interests of those who have hearing problems

***Can you tell something about your experiences in EFHOH?***

The differences/variation between the members were very big. From highly professionally guided countries such as Sweden and Norway, till almost unknown organizations in the South of Europe. The contacts with the countries in the East of Europe were important (already before the coming together of the Two Germany's. We tried to offer help (unfortunately no financial help). The Annual

General Meetings were linked with specific issues/topics like subtitling, employment etc. The hosting country presented her activities in the area of hearing impairment. I got to know a lot of engaged, pleasant people

***Can you tell something about the co-operation between EFHOH with IFHOH and IFHOHYP?***

The EFHOH was active right from the beginning, they did meet every year (IFHOH =Annual General Meeting every two years) The connections between IFHOH-EFHOH were good, the ICHOHYP was often not present – in some countries not present, or not present anymore. All of them had little money.

***What was for you personally the most important subject/moment/topic in your period?***

The biggest achievement was the organization of the IFHOH-congress in Montreux 1988. With the EFHOH it was the founding and implementation, the Annual General Meeting in the conference of Gent in the BIT-ILO and in Prato with “teletext”, the seminar in Stockholm and the Tagung (?) in Helsinki (loop systems for handy’s,) and the conference in Copenhagen, together with the IFHOH.

***What was the most sad or difficult moment/topic in your period?***

The needs of those with hearing problems were and still are not fulfilled. The care of the hearing devices often is not enough. I missed the good co-operation with professionals-ear specialist, producers of hearing devices etc.

***How do you see the future of EFHOH?***

I don’t know what happened after 2001, EFHOH as the Voice of those with hearing problems remains important. She has to bring up, together with the professionals their needs. Very important is the presence in Brussels. The EFHOH must be strong in front of the DEAF-organisations.

***Congresses, like Vancouver and the loop system conference, are very important. What do you think about their role in future?***

Congresses have many aims, they have to be planned carefully and the topics have to be attractive and interesting.

***What were you going to do in your free time when you had left the IFHOH/EFHOH board?***

I took up work/tasks in the church, in hospital; in the care for elderly people (since I am retired) I also look forward to free evenings and weekends (together with my wife!)

***Any other remarks?***

I wish the EFHOH a lot of success with what they do and I wish them inspired board members, who have powerful support, also in their own countries.

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# **International Summer Holiday for Adults with hearing loss**

## **6- 13 August 2011, in Szczyrk , Poland.**

*Lidia Smolarek-Best*

48 Adults with hearing loss in common from 9 different countries came to enjoy an EFHOH holiday together in the ski resort of Szczyrk, Poland.

The holiday came 5 years after their last holiday in Germany and 20 years after the last holiday for young hard of hearing people in the resort.

I would like to say that during the time we spent together I have seen the importance of such holidays, its value in developing new friendships, broadening our knowledge and supporting each other via co-operation and awareness rising.

I would like to point out the importance of co-operation as this is what has made this holiday special to me as the organiser.

***We support each other and find ways to overcome obstacles together.***

***We are a community of like-minded individuals.***

We made the history in Poland with the first ever speech to text reporting shown during the tours of the Salt Mine, Zywiec Brewery and Aushwitz-Birkenau. The reaction we were getting was really important.

The awareness rising was not only important for Poland, but many participants want similar mobile speech to text support implemented in their countries and that is a very positive impact.

Many thanks to Polish , Czech and Slovakian participants who took part in the EFHOH Seminar on the last day of the holiday. We had presentations from Ruud van Hardeveld about Cochlear Implants latest study, Vera Strnadova from Czech presented the speech to text project and Jan Lamby presented EFHOH.

I hope that the seminar helped with the new co-operation between European neighbours.

I would also like to express my gratitude to **Kela – The Social Insurance Institution of Finland** for the support and especially Kalle Tervaskali for organising speech to text reporters, to the translators for making our stay so enjoyable and to participants themselves for taking part in the holiday.

We all felt that the holiday went by too fast and I hope we will not wait too long for another one.

Special thanks to Dariusz Idziak and Michael Sadowski for the German and sign language language support.

One thing is for sure: we will not wait another 20 years for next holiday in Poland, and that's a guarantee!

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## Lillian Vicanek



In 1997 I was elected vice president of HLF (the Norwegian Association of Hard of Hearing). During my first year EFHOH arranged training courses in international work in Helsinki and Stockholm. Since I was not in an ordinary job, HLF asked me if I was interested in participating in these training courses and take care of HLF's international work.

I informed the board and the secretariat about my participation in these training courses and when I joined the board of EFHOH, I informed the board and regional and locals clubs of my work. I was often invited to annual meetings around the country. I always told something about the international work. I also established contacts that I could send the newsletter to.

HLF asked me in 1998 if I was willing to be proposed as a board member of EFHOH, then with Christina Wahrolin, HRF Sweden, as president. I agreed and in Budapest, spring 1998, I was elected as general secretary for EFHOH. In the beginning it was a difficult job. We had to send everything by post. Contact was not so easy as today. During my first year I got a computer to have contact with European Disability Forum, board members and member organisations.

The other persons in the board at that time were, president Christina Wahrolin, vice president Werner Bütikofer, Switzerland, The treasurer from Gouda in the Netherlands (Bas Koops) and a board member, I think from England. I was general secretary for 2 years, and during that time Marcel joined the board.

In 2001 I was elected as president at the Annual General Meeting in Budapest, and in 2003 I was an additional board member, paid by HLF to give Marcel support during his first year as president. During these years we struggled to make hard of hearing organisations visible within the European

disability network. Together with Christina I visited Brussels a few times.

We also had a board meeting there so that we could meet with the European Disability Forum and their very good lobbyist Sophie Beumont. Over the years this cooperation developed very well, and we managed to make hard of hearing visible and the understanding for the need of speech to text support in addition to induction loops was understood by those who arranged EU and EDF meetings.

When Christina left the EFHOH board she was elected as a member of the executive board of EDF (I think that is the name of it) during these years we joined the accessibility network, first in transport, where I was contact person, and later on about buildings. The cooperation with the deaf society improved very much when Marcel joined the board. He had easy access to Brussels and the organisation of the deaf. Many EU directives were improved these years and EFHOH had the possibility to make influence in issues of importance to hard of hearing persons.

Subtitling also became a major issue. Martin Davies from BBC and I were invited to Iceland to talk about subtitling. This meeting gathered deaf persons, hard of hearing persons and persons from other countries living in Iceland. Members of the government and the TV network attended the meeting.

We had a good cooperation with IFHOH and I had good and frequent contact with Marcia Dugan. We had joint board meetings and cooperate about Annual General Meetings.

The IFHOH congress and other congresses that set focus on the problems and possibilities will be necessary also in the future. There is still a lot of work to do before the society is accessible, and the development within medicine and science will also make progress in the future.

I have no free time. Since I left the EFHOH board I have been constantly working with accessibility both on local and national level. I also teach universal design for hard of hearing at the technical high school in Gjoevik, educating building constructors. They have now invited me to join them in the work of securing the quality of the work with assistive listening devices and acoustics in different kind of rooms, with different kind of building materials. If the project gets funding it will be a guideline to how to build and equip good listening surroundings for hard of hearing.

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## Christina Wahrolin



*In the beginning of the organisations some of the persons did not even want to have induction loop system. I remember a lot of annual meetings, which could not provide that.*

When I became a president of the Swedish Association of Hard of Hearing 1992 I heard about the international work for people with hearing loss. Representative from HRF attended a meeting in 1993. I think when we founded the European organisations – I think we were in Germany. Werner Butikofer (Switzerland) became the first president and I became a board member together with Mirja-Liisa (Finland), Christopher Shaw (United Kingdom) and Dick Klein Bussink (Netherlands). But after some years I became the president, Werner Butikofer vice president, general secretary Lillian Vicanek (Norway) and treasurer Bas Koops (Netherlands).

I would like to say that I had a very fruitful cooperation with both General Secretary Mirja-Liisa and Lillian. I really appreciate their work. The first years were difficult because IFHOH and EFHOH had some hard discussions. We in the European Regions would like to focus on the situation in Europe and try to strengthen the organisations of Hard of Hearing in Europe. We also

try to build a new organisation. There were also discussions about money. We also had discussions about who were our target group, who are we going to influence. Our European organisations should try to influence the European Disability Forum but also European Commission, the EU Parliament and so on. IFHOH should work to influence UN, but they were not interested in working with that.

Thanks to the Finish organisation we could have our General Secretary Mirja-Liisa in Brussels for six months trying to influence a lot of organisations working at the European level. At that time I was in Brussels quite often – I was a member of the EU Economic and Social Committee – and we had a very close cooperation – we took part in a exhibition and met a lot of people from different organisations. We also arranged a leadership training course for board members in the member organisations of IFHOH. The seminar was held in Stockholm and Helsinki. I think this was very important trying to learn more about – how to lead an organisation. We started to cooperate with European Hearing Instrument Manufacturers Association (EHIMA). In 1999 we held a conference together in Brussels – both IFHOH and EFHOH. I think it was very important when we changed name to EFHOH and could act as an organisation at the European level. We started also a newsletter.

From my point of view I think it is important to focus on what can we achieve together in EFHOH, for people with hearing impairment, to make people visible. But also trying to learn more about how we can do it, to work more strategic.

In the beginning there was more or less an organisation for individuals! I think it is also important to arrange meetings in the name of EFHOH showing how an accessible meeting can be. In the beginning of the organisations some of the persons did not even want to have induction loop system. I remember a lot of annual meetings which could not provide that. We were in Austria and our demands were – induction loopsystem in every meeting we had. But it was not – terrible. I think. If we don't have any understanding in our own organisations how can we think that the society would provide us accessible meetings and so on. So we have to start with ourselves.

I have been involved at the European level for a long time – both in EFHOH, in the EU Economic and Social Committee and also as a executive officers within European Disability Forum – unfortunately I have to say – EFHOH were not a strong organisation at that time if I compare with other organisations. Representatives from EFHOH must take part in different meeting and learn to tell their opinions in a constructive way, trying to influence, lobby and so on. That's why I think leadership training course is very important. It is not so easy to remember everything..... Today I am working as a full-time politician in my county council with health-care issues. But I am still involved at the European level as a politician working a lot with UN Convention for people with disability.

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# The OltreSuoni Project by onAIR Association

*By Giuliano and Giacomo Pirelli*

onA.I.R. - International Association on Respeaking - is the natural prosecution of the European Commission JRC VOICE project, which first developed respeaking as a technique to produce live TV subtitles for the Deaf and the Hard-of-Hearing. Their honorary president, Giuliano Pirelli, makes sure that this continuity is guaranteed, by constantly offering his support and expertise as the ideator and coordinator of the VOICE project.

onA.I.R. is a non-profit organization which promotes social, educational, cultural, and recreational activities by means of subtitling for the Deaf and the Hard-of-Hearing, through respeaking. Their aim is to reduce the gap between hearing, deaf, hard-of-hearing, and foreign people, by providing a direct access to real-time information through respeaking. To this purpose they organize training courses as well as debates, meetings, seminars, and conferences on respeaking and subtitling for the deaf and the hard-of-hearing. They also produce subtitles, both in real time and prerecorded for both live and prerecorded television programmes, films, theater shows, concerts, and other live events. onA.I.R. also collaborates with other associations and nonprofit organizations to diffuse respeaking as a technique to make it easier for deaf, hard-of-hearing and foreign people to get more involved in the society they also live in. The one they collaborate most, TDM 2000, is a non-profit organization promoting active citizenship, intercultural dialogue and European identity. TDM 2000 realizes several initiatives such as meetings, training courses, seminars and volunteering programs in Sardinia and abroad. Such activities are realized thanks to the most important programs on international mobility, such as “Youth in Action”, “Leonardo da Vinci”, “Erasmus for entrepreneurs” and “Anna Lindh”. In 2008, TDM 2000 formed an International network called TDM 2000 International which now includes 15 Nations.

The first project in collaboration with TDM 2000, called OltreSuoni, is a pilot project aiming at an experimental application of respeaking, namely radio live subtitling. In particular, onA.I.R. members subtitle “RadioXCaso”, TDM 2000 web radio, in real time from Italian into Italian. As a consequence hearers, as well as deaf, hard-of-hearing, and foreign people can follow “RadioXCaso” cultural, social, sport and political contents on their webpage with live subtitles, on an equal footing.

In the experimental phase three different groups of volunteers, composed of Italian hearing people, Italian deaf people and foreign hearing people, have “listened” for six months to RadioXCaso contents. The comprehension of each group was tested by means of comprehension, reception and perception questionnaires in order to understand the effectiveness of the project, whose main aim is to include both foreign and deaf people within the community they live in. Interaction is also possible by letting them actively interact with the rest of the population in a dedicated forum. This forum does not only create an interaction between participants to the forum itself, but it also influences on the content of the radio. After the six months of the experimentation, it was clear to the scientific committee how useful radio subtitling is and to what extent the experiment is replicable in other fields of active citizenship, like protection of the rights of the deaf, ethics of the use of social forums, and more prominently the safety and security of the citizen in case of emergencies. These are all aspects that traditional radio broadcasting alone cannot cover.

Even though comprehension, reception and perception of RadioXCaso contents are no more tested, the project is still on-going. Radio subtitles are provided from a remote workstation by onA.I.R. members and technology is provided by the Italian software house SyNTHEMA which assists the project with an on-line software accessible from the Web. The software can be accessed by

whatever mobile workstation connected to the Internet thanks to a dedicated on-line platform provided by the server itself. On the client side, the user dictates the text to be subtitled to the speech-to-text software program available on the on-line platform. The program automatically translates the vocal input into written text that is automatically sent to the editor's window, who edits and sends the subtitles on the radio web-page as subtitles immediately available by the radio users.

The project was not only revolutionary because it has first broken down the barriers of radio communication, but also because it has paved the way to a new form of social networking, allowing all members of the society to discuss on an equal footing, be they Italian or foreign, hearing or totally or partially deaf.

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## **Lidia Smolarek Best**



### ***When did you get for the first time in contact with EFHOH?***

After I lost the remaining hearing in 2008 I got in touch with Katja Vis, who was my friend from the times in the youth organization IFHOHYP many years before. However I was involved in the work of IFHOHYP since 1989 as a President of Youth Council at Polish Association of the Deaf. In January 2009 I received my CI and in April 2009 Katja invited me to EFHOH Annual General Meeting and Conference in London, where I met with the EFHOH Board. Those moments have defined my resolution to return to active advocacy again.

### ***Can you tell something about yourself and your work at local and on national level in your country?***

I have not been active in the Hard of Hearing movement since I decided to settle in UK in 1993 but it was my sudden hearing loss and the barriers I have faced during that difficult period that has prompted me to get back into active advocacy and volunteering. I have started at the local level with organizing weekends together, theatre trips and networking. Today I am a vice-Chair of National Association of Deafened People and a Trustee for UK Council of Deafness. I take part in the meetings at national level, participate in the Government consultations and recently I have delivered a public speech at Government Minister Level in UK. Whenever I am participating I constantly raise the needs of Hard of Hearing and deafened people. The deafened people especially face far more barriers in enjoying full social life.

***When did you join the board of IFHOH/EFHOH and why? Who were in the board? What have you done within IFHOH/EFHOH?***

I joined EFHOH Board in June 2010. Marcel Bobeldijk, Knut Magne- Ellisen, Jan Lamby and Ritva Liisa were in the Board as well at the time. What have I done during my tenure?

I participated in meetings forming the European Co-operation Platform of EU NGO's related to deafness. I have taken active part in the parliamentary meetings in Brussels raising the needs of access for Hard of Hearing and Deafened People including Parliament accessibility with loop systems and speech to text. I co-wrote together with Marcel Bobeldijk the "State of Subtitling in EU 2011" which was officially released during EFHOH Annual General Meeting in Vienna in 2011. I am very proud of this document which was a result of great collaboration between I, Marcel and the office of Lidia Geringer de Oedenberg MEP.

I have also negotiated with EDF to have EU subtitling campaign now in the hands of EFHOH as the best organization to lead on it with support of EDF. While EDF has already done huge amount of work in the legislation field, now it is the time from EFHOH to increase the lobbying campaign to implement the EU legislation in the Member Countries. As part of subtitling campaign I have delivered speeches during the key Media Accessibility conferences in London and Krakow. It is great to see closer collaboration developed with Media 4 All organizers as well. In the summer 2011 I have organized the International Summer Holiday for Adults with a hearing loss in Poland. It was great success and I am very pleased to see better awareness of the needs of Hard of Hearing people in Poland as the result. We had one day seminar during the holiday which brought East Europeans representatives, better collaboration with West Europeans. Our Board is making historic visit to Poland (Warsaw) in March 2012 to hold the Board meeting there and deliver short seminar on accessibility. Lastly I have participated in the historic meeting in Brussels, where hard negotiations took place in finalizing the name and details of cooperation agreement for European Platform of Deaf, Deaf Blind and Hard of Hearing. I continue to support anyone who needs any guidance and support from EFHOH and supporting the EFHOH Board with their inquiries. Part of my work at EFHOH was to be a candidate to EDF Transport Expert Group where now I am an adviser.

***What is your opinion about the role/tasks of EFHOH as a European NGO for HOH people?***

Our role is to advocate and lobby the EU level institutions which are relevant to our goals of accessible society but at the same time, I believe that our role is also to educate, mentor and support new, emerging organizations especially in the East Europe.

***Can you tell something about your experiences in EFHOH?***

It is an amazing experience to work at EU level. Nothing really prepares you for it really. You need an open mind, willingness to learn fast an art of diplomacy. The experience I have gained is as important as I am now equipped with many skills which are relevant to my everyday work as well. The support I have received from the other Board members, their willingness to share their knowledge and the time Marcel Bobeldijk spend in supporting me in the early days, I really could not have done it without them. During my time at EFHOH Board I have qualified as a Mentor and Trainer. Something I have never thought that I could do, so thank you to all for being an inspiration for me and giving me an opportunity to use it in practice.

***Can you tell something about the co-operation between EFHOH with IFHOH and IFHOHYP?***

IFHOH and IFHOH are already co-operating in many ways but it is IFHOHYP which needs to work closer with EFHOH right now. As EFHOH is now increasing the advocacy level and we are making an impact at the EU level, we need the younger generation to be ready to follow our footsteps. For example as one of the aspects of co-operation, EFHOH should be talking part in delivering presentations during IFHOHYP Studies not just during the IFHOHYP Annual General

Meeting. In order to increase our presence in Europe, we need this kind of close co-operation.

***What was for you personally the most important subject/moment/topic in your period?***

Oh, there were so many so I pick up 3; biggest one must be finalizing “State of Subtitling...” seeing academics and politicians using it as a reference point. Another one would be Summer Holiday in Poland and the lasting legacy of starting Hard of Hearing movement there. I have spent some time mentoring Hard of Hearing young people in Poland so to have 3 young Polish Hard of Hearing taking part in IFHOHYP Study in Strasbourg was an” icing on the cake.” Velotype support during meeting in EU Parliament in Brussels was another success.

***What was the most sad or difficult moment/topic in your period?***

The most difficult topic for me was the lack of finances at EFHOH. We have been so active but would be able to do so much more if the finances let us. All other EU NGO’s are far stronger in this respect and for EFHOH to succeed in becoming strong voice of Hard of Hearing in Europe, we need sound financial backing. Another thing which I found really difficult to deal with is the lack of awareness of the needs of Hard of Hearing and how much work is needed to make a reality the right of choice in communication access to so many Hard of Hearing in Europe.

***How do you see the future of EFHOH?***

I see EFHOH having much stronger role in the EU as the voice of Hard of Hearing and our role as NGO raising awareness of the 50 million Hard of Hearing and deafened people needs. One day, I hope we will our own office in Brussels as this is important to have a presence directly in the seat of power.

***Congresses, like Vancouver and the loop system conference are very important. What do you think about their role in future?***

I see those conferences as important part of advocacy but also as social and educational benefit for those attending. Our role is about bringing unified standards in loop systems installations and speech to text support as of same importance as sign language.

***What were you going to do in your free time when you had left the IFHOH/EFHOH board?***

Having experienced a very intense time in the Board I would like to turn this to the advantage for the national and local work within the organizations I am currently involved. I would like to develop stronger presence of Hard of Hearing community in Poland and to support stronger voice of Hard of Hearing in UK.

***Any other remarks***

It was a great honour to serve EFHOH alongside some of the most experienced advocates. They were great mentors for me.

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# ADVANCING TECHNOLOGIES

## Conference in London 4<sup>th</sup> March 2010

*by Lidia Smolarek Best*

The conference has been organised in collaboration between Ear Foundation and the UK Council on Deafness. UK Council on Deafness works with around 100 organisations in UK, who are having all different interest on deafness. The Conference focused primarily on the advancing hearing technologies and the consequences for us all. There are new developments in hearing technology.

### **Middle Ear Implants**

- suitable for people with remaining hearing cells in the cochlea
- after complications with ear infections
- work similarly to hearing aids with the difference that they assist by vibrations rather than amplifying

### **EAS (Electro Acoustic Stimulation)**

- for those with good preservation of low frequencies but loss of high frequencies
- the electrode is shorter than in traditional Cochlear Implant
- the electrode insertion is less traumatic for cochlea
- improves the hearing experience considerably better than traditional Cochlear Implant

### **BAHA (Bone Anchored Hearing Aid)**

- suitable for patients with conductive bone conductive hearing loss
- single sided deafness
- people suffering with middle or outer ear abnormalities
- chronic otitis media sufferers
- post tumour removal

### **CI (Cochlear Implants)**

- for people with sensorineural hearing loss above 85 DB
- used as part of treatment for tinnitus

### **The future of Cochlear Implants is really exciting with**

- cosmetics & practicality
- programming and processing
- drugs delivery through the electrode to stimulate the regeneration of inner ear hearing cell
- totally implantable “TIKI” System
- new, high density electrode ( nano- technology with expanding electrode)

The “next generation” implants are brain stem and vestibular implants.

The companies are also looking into making implants designed for older people.

The above list shows how far the technology has come from the first cochlear implant introduction.

Yet, the speakers' message is; "do not wait too long with the intervention".

While the technology advances, waiting for the best technology may hinder any good prospects of rehabilitation if the hearing nerve is not stimulated early enough. The assistive technology is also advancing very fast. Graham Hilton (Phonak) has presented a very exciting future as we will be able to walk into new buildings, which will have the Bluetooth incorporated!

We see the raise in the wireless digital accessory slowly pushing out the cored technology. New FM "INSPIRO" uses the use the dynamic FM in the classrooms. Bluetooth technology (iCOM) is another benchmark giving us unlimited connectivity in everyday life situations.

The Bluetooth technology is also used with Siemens mobile phones, "click & talk" device can assist with making calls without the use of neck loop.

Professor Adrian Davies, who is credited with starting the newborn screening programme in UK, wants to stimulate the use of innovation. He is calling on International Standards in hearing aids technology and the assistive technology. He has also presented us with his vision of NHS, where innovation, inspiration and patients experience is properly implemented.

The important parts of the conference were the actual users of the technology.

A 7 years old boy with bilateral cochlear implants, a hard of hearing adult with BAHA and profoundly deaf adult with unilateral cochlear implant.

While the first two were very pleased with their successes, the last speaker, Anna Herriman, despite her best efforts was not that successful. The reason was the late implantation at the age of 32. She spoke passionately about growing in the "deaf world" and having hard time in adjusting to CI. She had her implant 2 years ago, can hear environmental sounds and enjoys the music but understanding speech is still very difficult and she can't cope in the group situations. Anna still relies heavily on her sign language. She called for better information and rehabilitation of deaf adults who receive CI.

Lorraine Gailey (HearingConcern Link) gave the praise to the technology but asked if we are really catching up?

### **Does the technology improve the hearing?**

There is the danger, that many people will start seeing the hearing technology as the "panacea" for better hearing. In the reality, better hearing comes from better **use** of the technology.

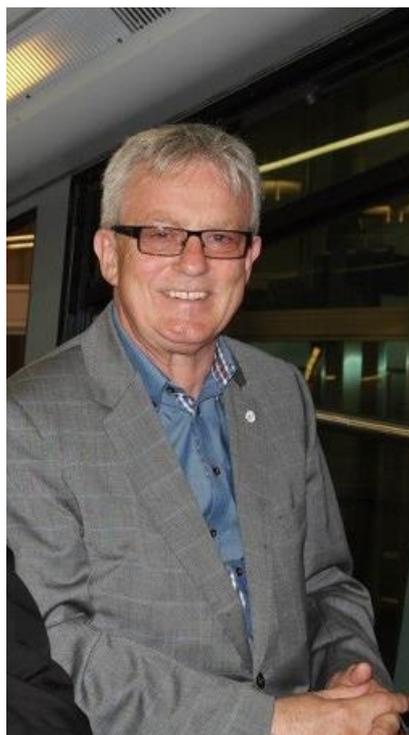
It can take long time for deafened people to get used to hearing aids or implants and they need the support services to derive the benefits from the technology. What had transpired is that while we are really advancing the technology, it can't work without the right people and services. There is distinct lack of focused rehabilitation programme and so called "post code lottery" in gaining access to both, technology and rehabilitation.

The UK health system focus 50% on technology, 40% on the price and only 10% on patients input. Its scandalous negligence of rehabilitation needs to be changed if we are going to see significant improvement in the use of the technology.

I left the conference thinking about the exciting future ahead of us but at the same time, I reminded myself that the technology does not restore the hearing loss. With the right support we can access much greater benefit only if we all work together; professionals and patients need to form a real partnership. Now, that sounds like really exciting future!

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## **Knut Magne-Ellisen**



### ***When did you get for the first time in contact with EFHOH?***

I was a member of the committee preparing the forming of EFHOH.

### ***Can you tell something about yourself and your work at local and on national level in your country?***

I started as Secretary general for the Norwegian organization of Hard of Hearing in 1986 and was working full-time until 1993. In 2004 I was elected as Chairman for the Hard of Hearing clubs in Oslo and in 2006 I was elected as President for the national organization of Hard of Hearing in Norway – which with its 55 000 members is the largest organization for disabled in Norway. I have decided to leave my position as President at our congress in June 2012.

### ***When did you join the board of IFHOH/EFHOH and why? Who were in the board? What have you done within IFHOH/EFHOH?***

I was elected as board member in 2007 and as Vice-President in 2010. I have been especially interested in building a strategy for EFHOH with both strategic and operational goals.

### ***What is your opinion about the role/tasks of EFHOH as a European NGO for HOH people?***

Since decisions made by EU have a big impact on all nations in Europe, it is important that we can be the voice of Hard of Hearing. Even if we have seen some improvements the last years, it is still many challenges!

### ***Can you tell something about your experiences in EFHOH?***

I think the voice of EFHOH has become stronger and stronger and that decision makers now are listening to us. We have – and shall have – a board who work well together and where each one is truly engaged in giving Hard of Hearing a better life.

***Can you tell something about the co-operation between EFHOH with IFHOH and IFHOHYOP?***

I think the relation is good. But there will always be some improvements. I am very happy that we in IFHOHYOP have so many engaged young people which I hope we will also see in EFHOH in the future.

***What was for you personally the most important subject/moment/topic in your period?***

Accessibility in general and building new organizations of Hard of Hearing.

***What was the most sad or difficult moment/topic in your period?***

Nothing special, but we need a better economy so we can be more active in areas where we should have been represented.

***How do you see the future of EFHOH?***

I am quite optimistic. We need strong national organizations, but with the changes we have seen in the importance of international work I think EFHOH will have a very important role in the future.

***Congresses, like Vancouver and the loop system conference are very important. What do you think about their role in future?***

We need meeting places like this. It gives inspiration in our daily work and also building the competence we need to do a better job for Hard of Hearing.

***What were you going to do in your free time when you had left the IFHOH/EFHOH board?***

I will still be working with matters for Hard of Hearing – at least on a local level. Besides that I am engaged in work among disabled in general. And I have five grandchildren...

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## ***Marcel Bobeldijk***



### ***When did you get in contact with EFHOH for the first time?***

In 1990 I participated one weekend in the Summer-camp of IFHOHYP in the Netherlands. In 1991 I attended IFHOHYP Summer-camp in the South of Poland. That was also the place where I met our EFHOH board member Lidia Smolarek- Best for the first time.

My first contact with EFHOH was in 1994. At that time I was the IFHOHYP Treasurer, and I represented IFHOHYP at the IFHOH BGM in Garderen, The Netherlands. At that time EFHOH was called IFHOH-Europe.

### ***Can you tell something about yourself and your work at local and national level in your country?***

In my daily life I am an HRM manager at the Tax office in The Hague. I worked many years for customs office at Amsterdam Airport as a team-manager and as HRM manager.

In my free time I am active in two committees of the NVVS, as chair of the committee for international affairs and I represent the NVVS in SOAP! The Dutch Subtitling platform of all the deaf and Hard of Hearing organizations.

### ***When did you join the board of EFHOH and why? Who were in the board? What have you done within EFHOH?***

In 1999 Bas Koops was Treasurer of EFHOH and he asked me to take over his job, also he asked me if I was able to attend the IFHOH-Europe board meeting in Florence/Italy. That was my first EFHOH board meeting at the time that Christina Wahrolin was President of EFHOH and Lillian Vicanek the General Secretary. I was Treasurer in the period 1999-2003 EFHOH and in 2003 I took the job over from the President Lillian Vicanek. At that time everything was new for me and I was very happy with the great support of Lillian, in the years 2003-2005 the period, that she was a board

member in our board.

At this moment my work in the board focuses at:

- IFHOH as EFHOH president, I am also an IFHOH board member;
- European Platform of HOH and Deaf organizations.
- Subtitling and Loops campaign;
- European Disability Forum;
- EFHOH Newsletter.

***What is your opinion about the role/tasks of EFHOH as a European NGO for HOH people?***

That is very simple. EFHOH is the European Voice of all hard of hearing people in Europe. EFHOH is the only organization which promotes the interests of hard of hearing people at all levels of the European Union. EFHOH is a member of the European Disability Forum (EDF) and since 2012 we work together with all other deaf and hard of hearing organizations in the European Platform.

We as the board have one goal: make Europe an accessible society so that we can say Europe is for all.

***Can you tell something about your experiences in EFHOH?***

We have good team work in the EFHOH board. It was very good that EFHOH started work with one important mean topic: Subtitling on TV. It was for me a great moment to speak about subtitling in European Parliament in Strasbourg, and later also at different other events. I will never forget the great World Congress in Helsinki, Finland and in Vancouver, Canada; two totally different congresses but both for me a big experience. The evening before the Loops conference 2011 we attended with 750 Hard of Hearing people a Musical. That was also great for me! In the theatre an efficient loops system and cart did the job for us. The warm and interesting contacts with so many Hard of Hearing people across Europe, who also work for a better life for hard of hearing people at local and national levels in all aspects of their daily life.

***Can you tell something about the co-operation between EFHOH with IFHOH and IFHOHYP?***

After the changes in the IFHOH constitution, I participated in all IFHOH board meetings. At first that was not always nice and simple. At the time when the late Marcia Dugan was the IFHOH president, we started warmer relationship between IFHOH and EFHOH. At the moment we have a good co-operation with the IFHOH and the IFHOHYP boards. Sometimes we have also our joint Board meetings.

I think that the time is gone that we can say EFHOH is a region of IFHOH. That would look much as a mother/child relationship. It is in my opinion more important to respect each organization and to accept that each organization is an independent organization. EFHOH has the focus for all the Hard of Hearing People in Europe, IFHOHYP has the focus for all the Young HOH people in and outside Europe. IFHOH focus their work to Hard of Hearing People outside Europe and IFHOH & IFHOHYP also have the role to advocate and lobby at International institutions and EFHOH about same work at European Union level. Let us talk and look at what we have in common, and don't forget we need each other to make Europe and the rest of the world accessible for Hard of Hearing people.

***What was the most important subject/moment/topic in your period for you personally?***

For me the most important topic is subtitling of TV programs. I am very happy that EFHOH now has loop systems as our second main topic. And it was a great and important moment to start working with an administration employee. That is a great support for me as President, and of course also for the other members in the EFHOH Board.

***What was the most sad or difficult moment/topic in your period?***

The lack of finances is the most sad and difficult topic all the years that I have been the President of EFHOH. It is important to understand that our participation at the different European Union meetings costs a lot of money. With the small budget that EFHOH has at this moment it is not possible for EFHOH to have a strong voice in Brussels. To support our members, to have Board meetings, for the website, brochure, newsletter, policy papers and to employ a secretary. Our members must understand that this all costs a lot of money and that EFHOH needs more income, such as membership fees, sponsor fees and financial support for special EFHOH projects.

***How do you see the future of EFHOH?***

I hope that EFHOH finds a new way to be a bigger NGO with an office and policy employee in Brussels. That way EFHOH really will be able to be the voice of all hard of hearing people at all levels of the European Union.

***Congresses, like Vancouver and the loop system conferences are very important. What do you think about their role in future?***

Congresses are very important because it makes us and our work more visible for our members and visible to the industry and policy makers. I see the congresses also as our show window and as the place where hard of hearing people as professionals by themselves meet other professionals.

And it is a very important part of our advocacy work at national and international level. The congress in Vancouver, Canada was great for me because it was a very good mix of advocacy, educational and social benefit. I think that it would be good and important to have an evaluation and discussion in the EFHOH and IFHOH boards after the world congress in Bergen/Norway; and to have a discussion later on with the members about how we see the future of world congresses.

***What are you going to do in your free time when you had left the IFHOH/EFHOH board?***

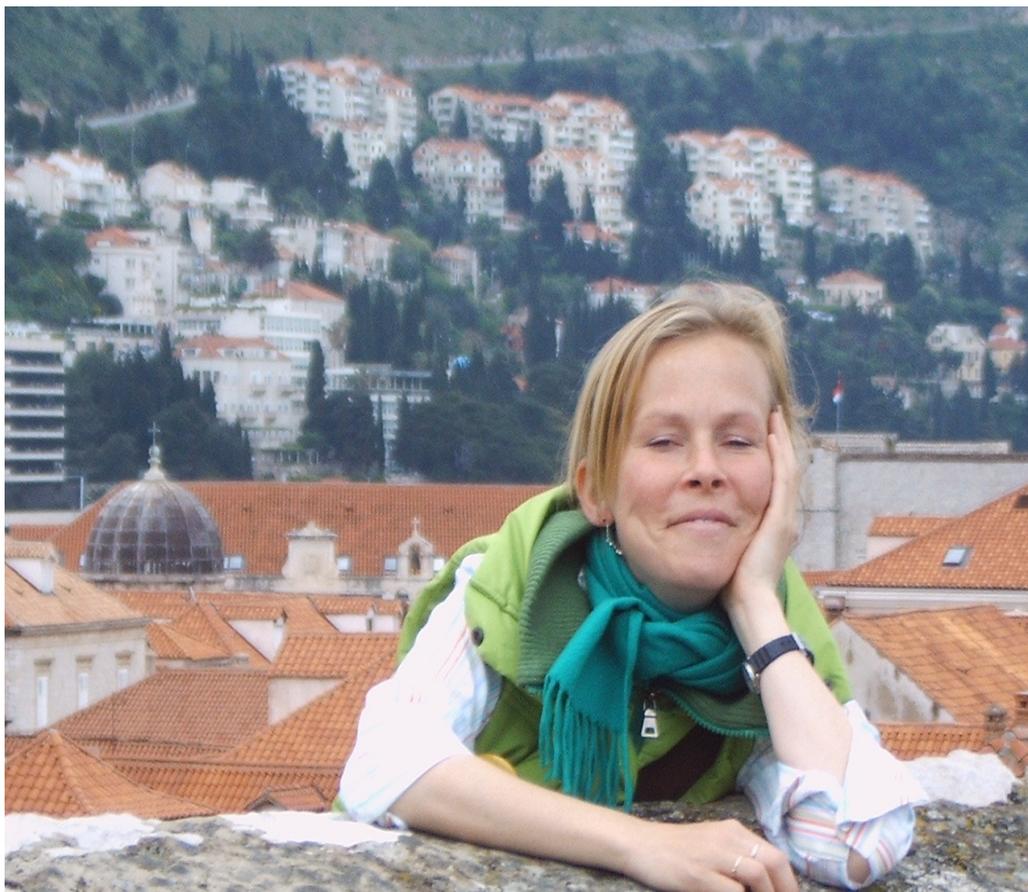
At this moment I will continue my work as EFHOH president and let's see what will happen after this period. Of course I will also continue my work for the NVVS, the Dutch hard of hearing organization with a special focus on Subtitling.

***Any other remarks***

Every day it is a great honour to be the EFHOH President, work together with this great team and it makes me happy to see, that we as a small ENGO, make Europe in small steps the Europe for all.

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## Katja Vis



### ***Can you tell something about yourself and your work at local and national level in your country?***

Hello, my name is Katja Vis. I have born in Finland 1973 but I have lived many years in the Netherlands. At this moment I'm living in Finland with my husband and four children. I have cochlear implant in my left ear and hearing aid in my other. When I was younger, I was very active in local and national level. At this moment I'm treasurer of IFHOH, but I will stop in the summer 2012. Six nice and rich years are enough for me.

### ***When did you join the board of IFHOH and why? Who were in the board? What have you done within IFHOH?***

I have been now 6 years in the board as treasurer of IFHOH. I think it was 2006 in Dubrovnik when I become board member.

### ***Can you tell something about your experiences in IFHOH?***

IFHOH is international Federation for all hard of hearing people. In the board we have five board members from different countries, also outside of Europe. With 5 people who are doing volunteer work, IFHOH may be proud of all activity's what he has done. Board members are having two meetings every year in the different countries. Every time we have lot of agenda points, so those meetings are usually 2 days long. We communicate by English and we are using speech to text support and loop system during our meetings.

### ***Can you tell something about the co-operation between EFHOH with IFHOH?***

Actually most important co-operation work is only possible because the president of EFHOH is also

board member of IFHOH. He/she is sharing all the information wish is needed.

***What was the most important subject/moment/topic in your period for you personally?***

Cochlear implant paper.

***How do you see the future of IFHOH and EFHOH?***

It's very important that older people understand that IFHOH/EFHOH needs also young people and that board members are not too long time in the board, that they give also possibilities for new people. I see that the future will be great for IFHOH/EFHOH.

***What are you going to do in your free time when you had left the IFHOH board?***

I will enjoy more with my family and making lot of garden works.

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# Jan Lamby



***When did you get for the first time in contact with EFHOH?***

Through conversation with former Secretary Monica Steorn, Sweden, and when attending national meetings in my organisation.

***Can you tell something about yourself and your work at local and on national level in your country?***

I have been active in my organisation over 25 years. The last decade I was the President of the County organisation, the District, which is an umbrella organisation for the local clubs.

***When did you join the board of IFHOH/EFHOH and why? Who were in the board? What have you done within IFHOH/EFHOH?***

I was elected Secretary in 2005. I was asked by our President at national level, if I was willing to be a candidate for the election. I have been interested of the international work and especially in the field of accessibility. This has been my main task in the board, apart from being the Secretary.

***What is your opinion about the role/tasks of EFHOH as a European NGO for HOH people?***

Very important, we still have a lot to do. We all often experience many examples of bad accessibility all around Europe.

***Can you tell something about your experiences in EFHOH?***

During my time we have had excellent boards, with good and open discussions. The only failure was when one board member very unexpectedly left in the middle of her term of office. But no one could be blamed for that, and the gap was filled up on the next election.

***Can you tell something about the co-operation between EFHOH with IFHOH and IFHOHYP?***

The relation EFHOH – IFHOH is a good one I would say. But there is still some constitutional uncertainty, because EFHOH once was created out of IFHOH and formally EFHOH is regarded as a Region of IFHOH. This situation is not clearly visible in the EFHOH Statutes. EFHOH's relation to IFHOHYP is good I suppose; and of course very important: We need to get the young people

involved, and when they leave the youth organisation because of age, we hope they will be interested to work in EFHOH.

***What was for you personally the most important subject/moment/topic in your period?***

Loop systems and subtitling; In the first topic EFHOH hosted through our Swiss member an International Conference in 2009, which was a success and was followed up by a second one. In Subtitling we have managed to get support from the European Parliament and the European Commission. A great improvement of our advocacy. Personally when we got an agreement with HRF in Sweden to have our “office” there; and administrative support from an assistant person there. That meant a substantial lowering of EFHOH Secretary’s work-load, which in turn enables myself to put energy and time in more important tasks.

***What was the most sad or difficult moment/topic in your period?***

Most difficult and something EHFOH still suffer from, was probably when the board member mentioned above left. Because she was responsible for the website, and no one of the remaining board members had sufficient knowledge to become a real web-master. Today it is extremely important to have a good and interactive website. Unfortunately for volunteer organizations like EFHOH, this costs a lot of money if it’s done by professional people.

***How do you see the future of EFHOH?***

I see a bright future of EFHOH, although there is a economic cloud hanging over us at the moment. I hope that we through better and closer contacts with the decision makers in Europe, are able to lower the current barriers to hard of hearing people in Europe.

***Congresses, like Vancouver and the loop system conference are very important. What do you think about their role in future?***

The world congresses are business that belongs to IFHOH; what they decide is up to them. But I think it is important for both IFHOH and EFHOH that these congresses continue to be a meeting place for both people from hard of hearing organizations and professionals; thus creating a good exchange of experience.

***What were you going to do in your free time when you had left the IFHOH/EFHOH board?***

As I am still in the board, I don’t think about that situation yet.

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# Signage

## an important part of accessibility to hard of hearing people

*Jan Lamby*

Ever since the first hearing loops were installed, one important part of the installation has been signage. A clearly visible and eye-catching sign, so that when attending a concert, or going to a meeting room, you immediately know to switch your hearing aid to the “T”-position. There are of course other kinds of accessibility to hard of hearing people: Tactile devices like vibrating alarm clocks; subtitling on TV etc. But the loop or other assistive listening system remains the most common and important accessibility to hard of hearing people with hearing aids.

During the past decades, many different solutions to the sign problem have seen the daylight. Almost every country had its own design of a symbol intended to show accessibility. For example in Scandinavia they used a big “T”, to show a room was equipped with a hearing loop. In Austria they used the logo of the ÖSB, the Austrian Hard of Hearing Association, and developed the design adding a picture of a “coil” together with the logo.

In 2000 the European Telecommunications Standards Institute, ETSI, adopted a new standard: “Human factors; Symbols to identify telecommunications facilities for deaf and hard of hearing people”. This standard specified a number of symbols for accessibility such as hearing loops; text telephony etc. The basic symbol is a graphic picture of an ear with a diagonal stripe across. The standard also offers possibility to add some smaller pictograms for different kinds of accessibility: A “T” for induction or hearing loops etc.

Despite this European standard, it was not recognized by all countries. A kind of resistance remained, because many people simply did not like the design of this standard. One of the objections is that the diagonal stripe resembles of a road sign, declaring “hearing is forbidden”. In North America however, they had used since long a symbol with a design very close to the European standard.

To the EFHOH Annual General Meeting, Annual General Meeting, in Dublin 2008 the Finnish Federation of Hard of Hearing, FFHOH, had motioned for an action to solve this mess. The aim was to create a new symbol, to be officially adopted by the organizations of heard of hearing people, EFHOH or IFHOH.

At a following joint board meeting of IFHOH and EFHOH, the boards commissioned two of their members to work with this project. They were Ahiya Kamara, Vice President of IFHOH; and Jan Lamby, General Secretary of EFHOH.

The project started with collecting information about the symbols currently used in connection with accessibility to hard of hearing people: Rooms of all kinds equipped with hearing loops; information counters at terminals for railway and at airports etc.

At a new joint board meeting, the boards finally decided to propose the Bi-annual General Meeting (BGM) of IFHOH in 2010, to officially adopt the European standard symbol.

The reason was that it would consume too much time, energy and money, if we tried to make a new standard. The BGM followed the proposal in Stockholm, Sweden in June 2010. By this decision, there is now only one symbol for accessibility to hard of hearing people which is fully accepted by the organisations of hard of hearing people. This design should be promoted and used world wide.

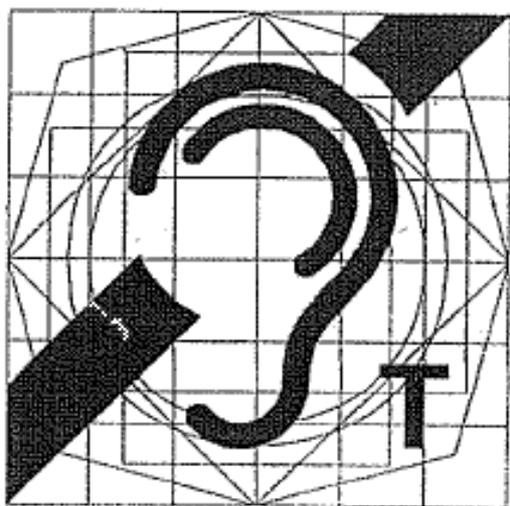
Of course the sign is no guarantee for the functionality of a hearing loop. In the EFHOH Accessibility Guidelines we provide good information about the installation of loops and accessibility in general.

A strong recommendation when using the symbol now adopted by IFHOH, is to add some kind of explanatory text or commentary. The symbol, with or without the small “T”, does not clear enough explain what kind of accessibility you provide. Examples: In a cinema it could mean it is equipped with a hearing loop; but it could also mean the film shown has subtitles. Another example: A hotel wants the show on their website they are accessible to hard of hearing people. Does it mean the rooms have tactile devices like vibrating fire alarm/alarm clocks or are the meeting rooms at the hotel equipped with hearing loops?

Correctly used, signage is an excellent way to provide information, not only on site, but to enable people making plans for visiting cinemas, museums, theatres and much more.

**Conclusion:**

Use this symbol!



**Note:** The standard does not specify the colours used in the symbol. The left picture is the geometrical construction of the symbol, taken from the ETSI standard.

A recommendation taking into consideration the needs of persons with visual impairment:

The ear, the stripe and “T” in white; the background in a sufficiently dark hue of blue, green, or black.

(In Sweden there exists a standardized method of measuring contrasts, provided by the Scandinavian Colour Institute.)

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## Ruth Warick



### ***When did you get in contact with EFHOH for the first time?***

My first contact with IFHOH was in 1984 when I attended the international congress in Stockholm, Sweden, then the 1992 Congress in Jerusalem. It was at the 2000 IFHOH Congress in Sydney that I first became aware of EFHOH.

### ***Can you tell something about yourself and your work at local and national level in your country?***

I am one of five founding members of the Canadian Hard of Hearing Association, established in 1977, the exact same year that IFHOH was established. I have served as President and in a number of capacities and almost yearly attend their national conference; as if this writing I am preparing to attend their 2012 conference in Ottawa.

At the local level I am secretary of the Vancouver branch and Vice-President of the Western Institute for the Deaf and Hard of Hearing.

My involvement in the hard of hearing movement goes back to my early twenties – pretty much all of my working life.

### ***What is your opinion about the role/tasks of EFHOH as a European NGO for HOH people?***

EFHOH does a tremendous job; my hat off to them and congratulations on 20 years as a thriving region and stalwart organization for IFHOH.

### ***Can you tell something about your experiences in EFHOH?***

I have attended several EFHOH Annual General Meeting's and conferences and thoroughly have enjoyed the friendship and connections with fellow hard of hearing persons in Europe.

### ***Can you tell something about the co-operation between EFHOH with IFHOH and IFHOHYP?***

IFHOH benefits from its close relationship with EFHOH through a position on the board of the EFHOH president. In this capacity, Marcel Bobeldijk has been a strong and effective contributor to IFHOH and has fostered close relations between our two organizations. As well IFHOH is pleased to connect with Karina Chupina, President of IFHOHYP, and through a new agreement looks

forward to an even closer relationship in the future.

***What was the most important subject/moment/topic in your period for you personally?***

There is no one topic for me as there are so many of vital importance. I know that without hearing aids I would have not been able to function so believe these devices are vitally important. Also important are assistive listening systems, captioning on television and at meetings, and effective safety and emergency devices. Accessible education is also a topic near and dear to my heart.

For IFHOH, the work around implementing the Convention on the Rights of Persons with Disabilities encompasses a multitude of issues and enables us an opportunity to make potential leaps in accessibility by networking with others in the disability community to bring about improvements. I see this as an important direction for IFHOH.

***What was the most sad or difficult moment/topic in your period?***

It is saddest to lose close friends and the passage of Marcia Dugan was sad although we can celebrate the remarkable life that she lived. She was such a warm and wonderful person. She first got me involved in IFHOH work by asking me to become editor of the IFHOH Journal.

***How do you see the future of EFHOH?***

EFHOH has made tremendous strides and can play a leadership role within IFHOH with newer member countries from around the world.

***Congresses, like Vancouver and the loop system conferences are very important. What do you think about their role in future?***

It is important for us to have opportunities to meet together to exchange ideas; we must also strengthen our use of technology to make events more accessible for more persons.

***What are you going to do in your free time when you had left the IFHOH/EFHOH board?***

I am not leaving for a while – I hope! So no free time but I do enjoy gardening, going to the gym, walking, movies and I would like to get pets again (cat and dog).

***Any other remarks***

Congrats again to EFHOH

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## Ahiya Kamara



***Can you tell something about yourself and your work at local and national level in your country?***

In the last two and a half year I am the Commissioner for Equal Rights of Persons with Disabilities in Israel. Before, I was one of the founding member and the first executive director of *Bekol – the Organization of Hard of Hearing People in Israel*. I am hard of hearing and have cochlear implants both sides and also have sight impairment. I live in Jerusalem and have a B.A in Psychology and M.A. in Education of the Hearing Impaired.

***When did you join the board of IFHOH and why? Who were in the board? What have you done within IFHOH?***

As the representative of Bekol – the Israeli Organization of Hard of Hearing people I participated in the IFHOH BGM in September 2002 in Ljubljana, Slovenia and in the IFHOH congress in Helsinki, Finland in July 2004. I was impressed with the international common needs of hard of hearing people and felt we all must unite to change our situation worldwide. The late president of IFHOH, beloved Marcia Dugan encouraged young hard of hearing people to be active in IFHOH and I joined the board of IFHOH in May 2006, after I was elected as the vice president in the BGM in Dubrovnik, Croatia. Also were elected Jan Peter Strongman from Sweden as the president, Ruth Warick from Canada as the general secretary and Katja Vis from Finland as the treasurer. Serving on the board as EFHOH's president was Marcel Bobeldijk from the Netherlands.

***Can you tell something about your experiences in IFHOH?***

It was a great opportunity for me to serve in IFHOH board. I could integrate my experience and knowledge of my work and studies in the field of hard of hearing in Israel with developing skills and experiences of the international arena. For example I could share my experiences from Bekol as a young and vibrant organization with other organizations in the world for the mutual benefits on one hand and to represent IFHOH in international forums like U.N and WHO meetings and to champion the hard of hearing voice in places we have never heard before on the other hand.

***Can you tell something about the co-operation between EFHOH with IFHOH?***

During the three terms (six years) I served in the IFHOH board most of the time I felt we were one organization with the same goals. I felt EFHOH is our voice in Europe and implement very successfully our common agenda in the continent. We wished to encourage such continental federations of hard of hearing people affiliated to IFHOH in all the other world regions to better serve the needs of hard of hearing worldwide.

***What was the most important subject/moment/topic in your period for you personally?***

It was most exciting to see how IFHOH become in the last six years a well respected international organization, especially with the cooperation of other international organization within IDA who wish to use the U.N CRPD as a vehicle to change the life of people with disabilities and the life of hard of hearing. Also I am proud of the “new face” of IFHOH we worked on: the new logo and brochure that was translated for the first time for many languages, the IFHOH journal and new website and the new position papers such as the accessibility guidelines and the position paper about Cochlear Implant. Of course I have to mention the annual meetings of people with hearing loss such as the congresses and BGM of IFHOH, where people with hearing loss from all over the world met and discovered that although we are coming from different socioeconomic background we are the same and have to face very similar challenges. It was great that the last board meeting was in my country, Israel, in Jerusalem and I hope the next BGM will be held in Jerusalem too.

***How do you see the future of IFHOH and EFHOH?***

I believe that one of our main aim is to encourage and support the establishment of organizations of hard of hearing people all over the world: in Europe (south and east of Europe) and all over the world, especially in Africa, Asia and South America. The well developed organizations have to support the new one. We need to have three levels of activity of hard of hearing people that will enhance their rights by themselves: the local state level, the regional level – in the same manner as EFHOH and the international level – IFHOH as integrator and to see all of the three levels as three aspects of the one organ – the hard of hearing people.

***What are you going to do in your free time when you had left the IFHOH board?***

(Laughing) I am not sure I will have free time. As the commissioner for equal rights for persons with disabilities in Israel I have a lot of challenges to face but if I will have more free time I would like to travel all over Jerusalem and Israel , to read, see movies and to develop an artist's skills. I always dream that one day I will expose my artistic hidden skills...

***Any other remarks***

IFHOH need to be stronger and we need the help of the well developed organizations to do our work. We especially need the involvement of new young hard of hearing leaders from around the world, from all the regions. I wish to thanks the opportunity I had to serve in IFHOH board and to wish the new board good luck!

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## APPENDIX

### Members of the board of EFHOH Europe 1993-today

<i>President</i>	Marcel Bobeldijk	Netherlands	2003-
	Lillian Vicanek	Norway	2001-2003
	Christina Wahrolin	Sweden	1997-2001
	Werner Butikofer	Switzerland	1993-1997
<i>Vice-president</i>	Knut Magne Ellingsen	Norway	2010-
	Siegfried Karg	Switzerland	2002-2010
	Werner Butikofer	Switzerland	1997-2002
	Christina Wahrolin	Sweden	1995-1997
	Mirja-Liisa Rontu	Finland	1993-1995
<i>General-Secretary</i>	Jan Lamby	Sweden	2005-
	Monica Steorn	Sweden	2003-2005
	Seppo Matinvesi	Finland	2001-2003
	Lillian Vicanek	Norway	1998-2001
	Mirja-Liisa Rontu	Finland	1995-1998
	Dick Kleinbussink	Netherlands	1993-1995
<i>Treasurer</i>	Ritva-Liisa Schading	Germany	2003-
	Marcel Bobeldijk	Netherlands	1999-2003
	Bas Koops	Netherlands	1997-1999
	Hans Maier	Austria	1993-1997
<i>Member</i>	Lidia Best	United Kingdom	2010-
	Knut Magne Ellingsen	Norway	2008-2010
	Ulla Konkarikoski	Finland	2004-2008
	Paul Zylberberg	France	2002-2004
	Cliff Docherty	United Kingdom	1998-1998
	Christopher Shaw	United Kingdom	1996-1997
	Christina Wahrolin	Sweden	1993-1996
<i>Add. Member</i>	Lillian Vicanek	Norway	2003-2005

## EFHOH board meetings

- 2012:** March, Warsaw/Poland  
**2011:** April, Vienna/Austria  
**2010:** June, Stockholm/Sweden  
**2009:** April, London/United Kingdom  
**2008:** April, Dublin/Ireland  
**2007:** April, Oslo/Norway  
**2006:** April, Dubrovnik/Croatia  
**2005:** April, Den Haag/Netherlands  
**2004:** April, Hamburg/Germany  
  
**2003:** April, Graz/Austria  
**2002:** February, Ferney Voltaire/France  
  
**2001:** March, Budapest/Hungary  
**2000:** March, Prato/Italy  
**1999:** April, Geneva/Switzerland  
**1998:** March, Helsinki/Finland  
  
**1997:** March, Brussels/Belgium  
  
**1996:** March, Helsinki/Finland  
**1995:** January, Paris/France  
  
**1994:** January, Graz/Austria  
  
**1990:** Berlin/Germany: Founding Steering Committee Euro-IFHOH
- June, Bergen/Norway  
October, Hamburg/Germany  
November, Vienna/Austria  
October, Bergen/Norway  
October, Houten/Netherlands  
October, Stockholm/Sweden  
October, Helsinki/Finland  
October, Zagreb/Croatia  
June, Helsinki/Finland  
October, Stockholm/Sweden  
October, Aarau/Switzerland  
September, Ljubljana/Slovenia  
November, Oslo/Norway  
November, Helsinki/Finland  
November, Brussels/Belgium  
October, Florence/Italy  
April, Stockholm/Sweden  
July, Istanbul/Turkey  
December, Fernet Voltaire/France  
May, Hvidovre/Denmark  
September, Berlin/Germany  
August, Graz/Austria  
May, Bensheim/Germany  
October, Olten/Switzerland  
September, Munich/Germany

# **EFHOH Annual General Meetings**

- 2012:** Bergen/Norway (BGM)
- 2011:** Vienna/Austria (Annual General Meeting)
- 2010:** Stockholm/Sweden (BGM)
- 2009:** London/United Kingdom (Annual General Meeting)
- 2008:** Dublin/Ireland (Annual General Meeting)+Vancouver/Canada (BGM)
- 2007:** Oslo/Norway (Annual General Meeting)
- 2006:** Dubrovnik/Croatia (BGM)
- 2005:** Den Haag/Netherlands (Annual General Meeting)
- 2004:** Helsinki/Finland (BGM)
- 2003:** Graz/Austria (Annual General Meeting)
- 2002:** Ljubljana/Slovenia
- 2001:** Budapest/Hungary
- 2000:** Prato/Italy
- 1999:** Geneva/Switzerland
- 1998:** Istanbul/Turkey
- 1997:** Copenhagen/Denmark
- 1996:** Graz/ Austria
- 1995:** Bensheim/Germany
- 1994:** Garderen/Netherlands
- 1993:** Bad Berleburg/Germany

## **International congresses**

- 2012:** Bergen/Norway
- 2008:** Vancouver/Canada
- 2004:** Helsinki/Finland
- 2000:** Sydney /Australia
- 1996:** Graz/Austria
- 1992:** Jerusalem/Israel
- 1988:** Montreux /Switzerland
- 1984:** Stockholm/Sweden
- 1980:** Hamburg/Germany