

European Federation of Hard of Hearing People

May 2008

Editor: Marcel Bobeldijk

EFHOH President letter:

Today it is Queen's day in the Netherlands, the day that we celebrate the birthday of our Queen. And tomorrow it is May 1st Labour Day in some countries, people are free of work. For me it is a very nice and long free weekend because in the Netherlands we celebrate our Liberation Day of the second world war on May 5th. In the country freedom festivals will be held, but it also the day that we remember that it is special to live in a free and democratic country/society.

I think that a society can be free and democratic when all citizens can participate in all levels of the society. And when I write all citizens, this includes disabled people. We as EFHOH and our members are working for a free society for hard of hearing people across Europe.

It has been very warm and interesting in Dublin for the EFHOH Annual General Meeting (AGM) 2008. We as EFHOH had a good board meeting before the AGM. It was fine that Peter Derbyshine the secretary of IHHA Ireland participated in our board meeting.

The EFHOH AGM and the conference on Saturday in the European Foundation was very good organized and the presentations of the different speakers on Friday and on Saturday were hugely informative and of great interest to our Delegates and also for the Members of IHHA. The EFHOH board will say some words of thanks to Peter Derbyshine and Michael Tighe for organizing this meeting in Dublin. Hannie Huigsloot has written an article about the EFHOH AGM in Dublin in this EFHOH newsletter. And when you like to look to some photo's you can have an look on facebook www.facebook.com Marcel Bobeldijk.

EFHOH is looking for a candidate/country that will organized the EFHOH AGM 2009 in the weekend of Saturday 25 of April 2009. Please contacted Marcel or one of the other EFHOH board members when you are interested to organized the EFHOH AGM 2009.

One weekend after our meeting in Dublin I was present at the Annual General Meeting of our friends of Euro-CIU in Luxembourg. This meeting was organized by the CI organisation of Luxembourg. It was nice for me to inform them about EFHOH and our work and to show them the very interesting book from Norway "A Hearing with CI". It is very fine and important to know that EURO-CIU are working in a close contact together for people with CI and hard of hearing people in Europe.

So as you maybe know EFHOH participates on European level in the standardization process of the services of hearing aid professionals. It is very important that the EFHOH members also participate in the standardizations process on National level. In this standardization process we talk about the fitting of hearing aids, the time that people can try the new hearing aids two weeks or three months, or is the time so long that the client is happy with the new hearing aids and of course about more topics? When you like to have more information contact Marcel Bobeldijk.

I hope to meet you at the IFHOH world congress in Vancouver this summer and I wish you a very sunny and nice summertime!

Kind Regards,

Marcel Bobeldijk
President of EFHOH

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EFHOH NEWS:

New Board Member *Knut*:

Dear Friends,

My name is Knut Magne Ellingsen. I' am born on May 13th 1944 and is divorced with two children and three grandchildren.

I have tinnitus and have been totally deaf one one ear since 1987. I worked as Secretary General in the Norwegian Organisations of Hard of Hearing (HLF) from 1986 to 1993. Since that I have been working in the organisation of heart and lung patients in the leader team in the administration, and is now director for the international department.

In 2006 I was elected as president of HLF. The organisation of hard of hearing in Norway is the largest national organisation for disabled and also the largest organisation of hard of hearing in the world. We have now 53.000 members and are getting around 250 new members every week. I think that tells us that HLF is a very active organisation in a small country (4.5 million), both trough our political work and trough the different activities we have in our more than two hundred local branches.

I have been working internationally for many years, both trough my work and trough different tasks in different organisations and umbrella organisations.

In my leisure time I like to walk in the forest and be at the fjord, but I'am also very fond of a good soccer.

I think it is important to have an umbrella organisations as EFHOH to work with questions which is important for us who are hard of hearing on European level. Accessibility in all areas is a very

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important matter to work with and so is also rehabilitation of hard of hearing. Representing one of the strong organisations in Europe with a lot of resources, I also think EFHOH shall support building new organisations and work to strengthen small ones.

The e-mail address for EFHOH

The EFHOH email address is efhoh@hrf.se

EFHOH AGM 2008 in Dublin:

By Hannie Huigslot

On 26 March the European delegates and IFHOH board members were welcomed by the Dublin team of the hard of hearing organisation. March 27th the EFHOH board held their meeting, followed by a warm reception for all in the Elm Park Golfclub. Everyone shared their toasts, experiences and national stories.

On March 28th the annual general meeting was held. The meeting had been organized by the Irish hard of hearing association (IHHA).

Peter Derbyshire and Michael Tighe had taken up the work of the previous Irish chairman Pat McKenna, who passed away on January 30th. Pat McKenna had initiated and developed the Irish association and the conference and AGM. They were aided by Freda Keenan and Aideen Foran. The Dublin team have the advantage that they have many members and friends. They cooperate with many organisations and politics.

The EFHOH chairman, Marcel Bobeldijk opened the meeting. He was very happy to see so many delegates and observers. He reminded us of the Oslo AGM in 2007, which had brought many ideas and initiatives. The EFHOH board now consists of 4 people, since Ulla had left the board since she is a mother. With the elections Siegfried Karg was re-elected. There were two candidates for Election: Anna Klemittila and Knut Magne Ellingsen. Anna is a promising designer, who has experienced the consequences of being hard of hearing herself. The other candidate was Knut Magne Ellingsen, who is chairman of the Norwegian hard of hearing association in Oslo, has worked with handicapped people also and is hard of hearing. Knut was elected.

On 27 March 2008 the Dutch association of hard of hearing people, the NVVS, had their 100th anniversary, so Marcel Bobeldijk celebrated them. Also their history was described. The EFHOH have worked hard on different topics, the most important being:

- tv subtitling
- e-accessibility (in cooperation with ANEX and EDF, and the memo of understanding to the European commission)
- a motion by the Finnish federation for hard of hearing, about a standard symbol for a T-loop
- services offered by hearing aids professionals in different countries.

The board are eager to receive feedback by users and organisations. The EFHOH board are very happy with their new employee. She is Lillian Ebadi Lindqvist, from Sweden. She works with the Swedish hard of hearing organisation (HLF). Speeches were held by Jan Lamby, Noora Pertinen about IFHOHYP and Jan-Peter Stromgren about IFHOH. Also the European/Dutch federation of parents of hard of hearing children was introduced by Guus Coenen, it will be

published in the newsletter.

The minutes of the AGM in Oslo 2007 were approved. The annual report was approved. Jan Lamby focused on the work that has been done, together with the EDF (European disability forum) and other organisations. Questions were asked about the financial side of the secretariat, this was answered by the chairman; and about the contacts with the non-paying members, some countries are represented by someone else, and the IFHOH board will decide on the finance. The annual report was approved. The financial report was explained by Ritva-Lisa Schaeding. Questions about new conventions about induction loops, which has been budgeted. Marcel Bobeldijk explained that this will be planned for 2009, together with the invitation for a new host for the AGM meeting next year. The auditor's report is to be sent to all for comments.

Other topics:

- Public transport, telecommunication and subtitling.
 - Organisation and partnerships:
 - EDF, European disability forum. This is a very important partner.
 - WHO Europe, also good contact with EUROCI, FEPEDA and EUD.
- These are the European association for cochlear implants, parents organisations of hard of hearing children and European deaf organisations.

Facilities and service.

- The use and quality of induction loops is discussed,
- a standard symbol for induction loop in public buildings, in transport, tv etc.
- alarm systems for hotels

Several speakers discussed the Finnish motion and the symbols that are used now. These will be discussed further, also in politics. It must be made clear that there must be a clear answer to this. The chairman explained that the first step is to get an understanding which symbols currently exist in standardisation, and which are lacking. Then get a symbol assigned to one of these. He also said EFHOH should really start lobbying for a legal obligation

Siegfried Karg will write an article for the newsletter about the developments. Anna explained it is also an image thing. The motion is changed to the words. Suggest that EFHOH works to ensure symbols are standardised. -This item will be put on the agenda for 2009 AGM.

2008 July World Congress in Vancouver Canada. IFHOH general secretary Ruth Warick gave a warm presentation for the congress in July 2008. So far 400 people have registered, and many people who were in Dublin are hoping to attend Vancouver conference on global community.

Noora the secretary from the IFHOHYP, from Finland explained about the work and developments of their very active organisation. They have 13 members, and they hope to get new members from Pakistan and Canada. Their main priority for next year is to make themselves stronger, going to improve and renew the constitution, which is a process for a whole year. This will be discussed next AGM.

They also want:

- to improve communication inside organisation,
- to make a new website
- to make a strategy plan
- and to make a political agenda.

Recently they have developed a multimedia project, funded by the Council of Europe. Also they have made a very interesting brochure: 'What it is like to be young and hard of hearing in Europe'. Also a dvd

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will be made ready for congress. They have applied for membership in the European Youth Foundation, the EYF, to be more active. This year they are holding a Summer Camp in Slovakia from 26 July to 8 August. Information is available to all, also for Vancouver. She concluded by inviting young and new members, between 18-35. They are a very Organisation.

The next presentation was held by Jan Peter Stromgren. It is very unique that we have our own conference, so I think it's very important to say it again - we must try hard to support it in many ways and the best way is to participate! Jan Peter Stromgren gave some information about IFHOH. IFHOH is a very active organisation. Jan Peter is the president, vice president, Ahiya from Israel; then we have the general secretary, Ruth Warick. Treasurer Katja Perttilla. Katja is from Finland/Netherlands and Ruth is from Canada. They wish to expand the board, because at the moment there are no members in Africa, or Latin America.

So that is a very big goal for us in the future, to get contact with hard of hearing people in these areas and get them organised.

In Asia, we have organisations and I think they are coming on in that area. Experience in the international field. They are members of the IDA, after Marcia Dugan's idea. This is the International Disability Alliance. From that IFHOH has formed from a world organisation outside the disability community to being an organisation inside the disability community.

Through IDA, we are partners with 7 other worldwide organisations and we are the partner for the UN system. It's with IDA they are discussing different things. The IFHOH journals give a lot of information. Ruth Warick produces everything they are doing in the field.

Inside the IDA system, they have started the IDA - CRPD Forum. It's a forum for the disability community to monitor the action that is taken about the new convention. Marcia Dugan was in Amman, Jordania, representing hard of hearing people.

Guido Gybels from the RNID, royal national institute for deaf people, gave a speech on 2 issues currently playing at the European level. Both are related to the legal environment.

One subject relates to decisions about European legislation.

1. The review of the electronic communications framework.
2. Accessibility. A memorandum about tv and subtitling had not worked, but now they are working on minimum requirements for proper communication.

Annie's

Raymond -- from the Netherlands. Personal experience with hard of hearing people. He gave a presentation about their Annie's company. Especially the importance of real time text communication was pointed out. Deployment of real time text is also one of the main EFHOH targets for 2008 and 2009. This goal has a good chance of being achieved in this timeframe. Starting this summer, real time text will be available. It will be presented in Vancouver Canada. It also fits the central theme of that congress very well - global community of communication and establishing a world standard for deaf communication very well. Text is a very important bridge from the deaf and hard of hearing world to the hearing world and vice versa. He implored on all delegates make their national phone operators or governments aware of this possibility of real time text now. This way, after the next meeting of EFHOH or after Vancouver, everyone can say to each other I'll call you next week, like any hearing people would. So please notify your national operators to encourage real time text in your own country.

Arnoud van Wijk:

He held a speech about the Internet Society, most people working with organisation for deaf or hard of hearing people. In 1992 this non-profit organisation was started, more than 38,000 people who are members, more than 90 chapters, all over the world. The Internet society: all people will benefit from internet, the society is taking part in connections, creating all the protocols you need. Everything you use on computer, strong link in future internet and past, one of important things you have done is stimulating countries that have limited internet access, by satellite, solar, antennae. Located in Reston Virginia, USA and Geneva.

The need for the internet community helps society we are creating, motto of the society is: 'Internet is for everyone!'

- including deaf and hard of hearing people
- including blind, and other disabled people
- all people!

A large organisation, guided by principles,

This morning a new principle was adopted: NO DISCRIMINATION. ISOC has standards.

We offer people real time text, using internet for everything in society. This is unique situation in society for first time to start helping disabilities, all internet related. We have to make sure all people have internet, anywhere, regardless of anything. We trying to influence standardisation to the law. ITS are already having meetings to make sure standards are more accessible. One of the largest standard organisation for years I have been working through text telephones, many meetings, many organisation are now putting more attention to it, carry more weight. We want to make it accessible, try to fill in the gaps, create the goal. There is a new version of the general guidelines which is now called An Inclusive Society, Being Accessible to hard of hearing people. In the near future, the general guidelines should have a new part about accessibility not only in taxis but also air and rail.

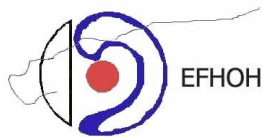
The chairman wished everyone success with his work, and the 29 th of march there was to be an interesting conference.

EFHOH AGM 2009:

CALL FOR EFHOH AGM 2009:

Dear members we as EFHOH board are looking for a candidate that would like to organise the EFHOH Annual General Meeting (AGM) in the spring of 2009. We as board like to have the AGM in the weekend of Saturday 25 April 2009. When you as a member like to and are able to organise the EFHOH AGM 2009 please contact Marcel Bobeldijk. Of course the EFHOH board will give you information and will support you at organising the AGM. Please send your positive reaction before the 1st of June to Marcel Bobeldijk. At the IFHOH world congress in Vancouver, we will inform the EFHOH members where and when the next EFHOH AGM 2009 will be held and of course we will also inform you in the next EFHOH newsletter.

Thanks.



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EFHOH Board Task Allocation:

Marcel Bobeldijk: Contact person EDF and IFHOHYP, board member of IFHOH, member of INCOM/TCAM, Subtitling, Telecom and Public transport and editor for the EFHOH newsletter.

Siegfried Karg: Contact person German speaking members and contact person industry/sponsors and the technical subjects

Jan Lamby: Secretary's work contact person to all our members and responsible for mailing lists etc; accessibility of the built environment; currently editor of the EFHOH website.

Ritva-Liisa Schädig: Treasurers work and look to new sponsors/funds

Ulla Konkarikoski: leave the EFHOH board.

EFHOH Program 2008

24+ 25May	EDF AGA Ljubljana/Slovenia, Marcel
1 – 5 July	IFHOH world congress Vancouver and IFHOH AGM, all the EFHOH board members

EFHOH Documents and Presentations on the website:

- Statement about UN Convention on the rights of Persons with Disabilities;
- EFHOH Survey on accessible e-communications;
- EFHOH Guideline for an Inclusive Society;
- EFHOH Comparison of Subtitlings.
- And more see www.efhoh.org

IFHOH NEWS:

CHHA-IFHOH world congress 2008:

When: July 2-July 6
Where: Vancouver Canada
Questions: congress2008@chha.ca

"A Global Community of Communication"
Register now for the July 2-5, 2008 joint Canadian Hard of Hearing Association and International Federation of Hard of Hearing People international conference being held at the Sheraton Wall Centre in Vancouver. Practitioners, policy-makers, service providers, family members and consumers from around the world will network with each other, share best practices, and learn about important issues in promoting hearing accessibility, services and programs for improved

communication and quality of living for hard of hearing people. Book by **Feb. 29** for the 'early bird' registration rate.

Featured Keynote Speakers

- Johan Hammarström, with panel members Ahiya Kamara, Duong Phuong Hanh and Jan-Peter Strömngren, discussing his air flight around the world and challenges faced as a hard of hearing pilot.
- Dr. Kelly Tremblay on how sound is relayed and processed beyond the ear and its impact.
- Jan-Peter Strömngren, Marcia B. Dugan and Charlotta Göller on the United Nations Convention on the Rights of Persons with Disabilities and its importance for hard of hearing people worldwide.
- Dr. Charles Laszlo and Dr. Kathy Pichora-Fuller exploring the current state of hearing accessibility and ways to foster and coordinate hearing accessibility research world-wide.
- Gael Hannan presenting a thought-provoking look at the reality of life with hearing loss during her performance, Ear Rage: Life on the Hearing Loss Road.

Besides plenary sessions over 57 workshops and panel presentations will be delivered as well as 12 poster sessions, all of this within four days, from July 2 to 5 at the beautiful Sheraton Wall Centre in Vancouver.

Altogether some 102 presenters will converge on Vancouver, Canada for the Congress. This is the largest contingent of presenters by far of any who have attended at CHHA Conference.

Special Conference Activities

- **Special opening reception** on Wed., July 2 with flag marching by hard of hearing youth.
- A Karaoke Night of performance and fun on Thurs., July 3.
- A **Special Reception** sponsored by Cochlear Corporation on Fri., July 4 and a closing Banquet on Sat., July 5.

Full details, including Congress program, hotel reservation information, registration, and contact information are available online at www.chha-ifhohcongress2008.com.

IFHOHYP news:

IFHOHYP and advocacy for hearing loss and human rights in Europe

By Karina Chupina, IFHOHYP president

IFHOHYP – who are we?

IFHOHYP is the only international non-governmental federation for national and regional youth organizations that are dedicated to hard of hearing young people throughout the world and is independent of sex, race, religion, nationality and politics. Our greatest priority is improving the quality of life of hearing impaired youth and promoting equal rights for hard of hearing young people at all levels of society.

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We raise disability awareness on national and international level through activities run by and for hard of hearing young people aged from 18 to 35.

The overall long-term aim of IFHOHYP is to increase participation of hard of hearing youth in civil society and empower them in addressing disability concerns to wide public and the International institutions.

IFHOHYP is counteracting stereotypes towards hard of hearing people and expresses their needs through action at many different levels - educational, informational, and political.

Today, IFHOHYP members are: Spain, the Netherlands, Serbia, Russia, Italy, Czech Republic, Finland, Slovakia, Poland, Sweden, Bulgaria and Switzerland, Pakistan. We are expanding from being mainly European to forming an international organisation.

Norway and Canada are on their way to membership. Welcome!

Training for hard of hearing youth

The most important IFHOHYP activities are regular study sessions on a specific topic held regularly every two years in cooperation with the Council of Europe (www.coe.int) Directorate of Youth and Sport (www.coe.int/youth)

Every time, about 30 selected participants from 14-18 countries come here together for one week. The topics of some previous sessions were: "Knowledge Transfer – how to make a campaign on hearing disability", "Building communication for hard of hearing youth: breaking barriers and stereotypes", "Safeguarding human rights of hard of hearing youth: coping with discrimination and violence in education and employment", "Leadership skills and developing necessary competences with hard of hearing youth – Getting strong in the future".

At the study session in 2006, policy recommendations on Access to Information, Access to Education, Access to Employment and Access to Technical Means of Rehabilitation were created and submitted to the Council of Europe.

Study sessions is based on highly interactive methods aimed at raising self-confidence, ability to stand for one's rights and to advocate. Skills-building workshops such as workshops on communication, conflict management, leadership, teambuilding, public speaking, facilitations, human rights education, combating negative stereotypes, fundraising, project management are a highlight of every study session.

A participant once described her study session experience as "one of the most fragile yet invaluable experiences of my life...it was good to watch people initially shy + quiet gain confidence to make attempts to participate more, make their voices heard, to contribute to the group task".

It is mainly only through trainings that youth with disabilities can develop such attitudes as tolerance to others, motivation for social action, develop self-awareness and needed skills for project/youth work as they can rarely be learned at a school.

Foreign language study is not always accessible for hard of hearing youth, too. Therefore IFHOHYP study sessions, meetings and summer camps are a unique chance for young people to learn or practice English in a comfortable atmosphere.

Advocacy and awareness-raising about hearing loss

Multimedia project "**What is it like to be young and hard of hearing in Europe?**" was aimed at raising awareness about hearing loss among the society and in decision-making institutions. 1500 brochures were published in 2007 and most of them distributed to organisations at IFHOHYP. Multimedia DVD with movies, photos and articles from different countries is awaiting its production and might be completed in spring 2008.

Research Project "**Hard of hearing young people in Europe: developing strategies on access to equal participation, social**

inclusion and protection of human rights" is taking place today; extensive developed questionnaires on the situation for hard of hearing in different countries across Europe will be sent to leaders of organisations for hard of hearing and hard of hearing individuals. Result of the carried out research will be policy recommendations to the International Institutions.

Lobbying and political activity

IFHOHYP is an associate Member of the *European Disability Forum*, the platform for disability organisations in the European Union. *This means that IFHOHYP is able to send proposals for disability legislation, actively contribute to EDF Youth Committee work, take part in and to send delegates to the EDF events such as the European Day of People with Disabilities.*

IFHOHYP is also represented in the *Advisory Council on Youth (AC)*, Council of Europe. AC is a statutory body comprised of only 30 selected representatives of international youth organisations that provides opinions from the youth NGOs on Council of Europe youth sector activities and ensures that young people are involved in the Council's other activities.

Within Advisory Council, IFHOHYP raises disability issues and can affect the agenda of the Council of Europe Youth and other sectors e.g. by calling for more attention to disability representation at the Council of Europe events. By the way, IFHOHYP is the only international youth disability organisation ever represented in the Advisory Council.

Today, IFHOHYP is also the only *international youth disability* organisation that is very actively cooperating with the Council of Europe and the European Commission.

EDF News:

EDF sends open letter to European Commission President Barroso:

Following public announcements made by European Commission officials that **a proposal for a European directive fighting discrimination against disabled people** will be proposed to the College of Commissioners at the end of June as part of a comprehensive 'Social package', EDF sent an open letter to President Barroso welcoming this decision.

In its open letter, EDF welcomes the response given to the "1million4disability" campaign which gathered more than 1.300.000 signatures as the first citizens' initiative that is followed up by the European Commission. The letter also refers to the significant step of such a decision in the implementation process of the UN Convention on the rights of persons with disabilities.

EDF also call for the proposed legislation to adequately address the situations of multiple discrimination in which all disabled persons may find themselves regardless of age, sex, religion or belief, ethnic origin or sexual orientation.

Finally EDF calls on the Council, the Member States and the European Parliament to carry forward such disability legislation which will bring citizens closer to the European Union.

All EFHOH members are also strongly encouraged to disseminate the letter to all their contacts at all levels.

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EDF participated in CEN/AFNOR workshop on the need for standardisation in the area of accessible tourism services (Brussels, 13 February 2008)

On the 13th of February a workshop was held in Brussels, organised by CEN (the European Standardisation Body) and AFNOR (the French Standardisation Body) on the topic 'Accessibility to Tourism Services'. This workshop was the occasion for presenting the results of the investigation that AFNOR has undertaken during 2007 on behalf of CEN on the needs for standardisation in the area of accessibility to tourism services. It was also a good opportunity for all stakeholders to meet and to share their ideas and concerns.

On behalf of EDF, Policy Officer Maria Nyman made a presentation, highlighting in particular the need for standards on the use of accessibility symbols by tourism providers and the need for independent assessment by accessibility experts on the use of these symbols, and the need for training of all personnel working in the tourism sector on disability awareness and disability equality. Standards might be the only way for progressing in this area as the EU has very limited legislative competence in the area of tourism.

It was underlined by the ANEC representative Ms Nina Klemola that it is important to have a very clear scope when discussing standards in this area, as services are intangible. ANEC underlined also the need for a more systematic use of the CEN/CENELEC Guide 6 (guidelines on how to ensure design for all in standards-writing) whenever elaborating new standards.

Most participants agreed on the utility of standardisation on the use of accessibility symbols and standards on disability-awareness training as proposed by EDF, as accurate information about the accessibility at the tourism destination, and welcoming of tourists with disabilities, is of crucial importance. It was however reiterated at several occasions during the workshop that the same level of service and training could not be expected from very small business as from the larger hotel chains and tourism businesses.

AFNOR will now prepare their final report to the Commission where their conclusions for the need of standardisation on accessible tourism services will be included. EDF will prepare a response to this final report which should be ready before April 2008.

For more information, please contact Policy Officer Maria Nyman, maria.nyman@edf-feph.org

News from our Members:

Acoustic tumor

By NVVS and translate Hanny Huigsloot

The Dutch committee for acoustic tumor

The committee endeavours to assist people affected by an acoustic tumor, clients who are following the preparatory treatment and clients who have had treatment for the tumor.

She sees to it that their interests are looked after very well in cooperation with ENT specialists and audiological centers. The committee keeps the clients and professionals informed about the condition by:

- the bi-monthly magazine Horen ('hearing')
- the website of the NVVS www.nvvs.nl (dutch national association for the hard of hearing)
- brochures
- contact- and information meetings for acoustic tumor patients and their partners.

Every year the committee for acoustic tumor of the N V V S organizes several regional contact meetings and one national day for all people. They give speeches about all kinds of items and subjects that are related to acoustic tumor.

People can follow these speeches and hear information by experts and they can ask questions. They can get in touch with experts and other patients who have similar questions and they can discuss their daily problems and the consequences for daily life.

Apart from this the committee also assembles all information related to an acoustic tumor.

This implies a lot of work and responsibility, because with this condition several disciplines are involved, such as:

- ENT specialist or neurologist for the MRI-scan
 - for diagnoses
- ENT specialist or neurologist
 - for operations
- Radiologist or radiotherapist
 - for radiation
- Eye specialist, mime therapist, speech therapist
 - for treating facial diplegia
- Fysiotherapist
 - for
- equilibrium treatment
 - for problems
- Psychologist
 - for psychological effects
- at the processing of any mental
 - for the obtaining of medical devices

The tumor mostly prevailing in the adult presents itself as a solitary tumor, originating in the nerve. It usually arises from the vestibular portion of the 8th nerve, just within the internal auditory canal. As the tumor grows, it usually extends into the posterior fossa to occupy the angle between the cerebellum and the pons.

The correct medical term is **vestibular schwannoma**, because it involves the vestibular portion of the 8th cranial nerve and it arises from Schwann cells, which are

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responsible for the myelin sheath in the peripheral nervous system. Nearly always this tumor is benign.

A different name for this tumor is : acoustic neurinoma or vestibular schwannoma. There are also forms of this tumor which occur in the shape of neurofibromatosis. This is an hereditary disorder where people have brown spots all over their body and have wart-like spots over their skin. One of the sorts of neurofibromatosis is the disease of Von Recklinghausen.

The cases are mostly discussed within a team of experts (ENT-specialist, neuro-surgeon, radiologist and a radiotherapist). Here the options for treatment are discussed, after which the individual patient can make a cell-considered choice. There are 3 main treatments:

1. Operation: the tumor is removed by an operation.
2. Stereotactical radiation. Growing of the tumor is halted by a very strict positioning of the radiation.
3. Wait and scan. Sometimes there is a tendency to watch and follow the situation at a relatively small tumor or minor complaints.

Symptoms/complaints:

Symptoms may be:

diminuation of the hearing
unilateral loss of equilibrium

tinnitus

headaches

disturbed perception of the facial sensations

Book: "A Hearing life with CI"

During the EFHOH AGM in Oslo we had a visit to Briskeby School of Competence where the main subject of the day were Cochlear Implants. One of the speakers was Inger Anita Herheim, physiotherapist and specialist in psychomotoric physiotherapy. She has written a book about her own experiences with CI and how to cope with the problems as a part of the ReSonare project.

"A HEARING LIFE WITH" Cochlear Implant, training, learning and change".

The Resonare project is carried out as a commission from the Directorate for Health and Social Affairs and the National Support System for Special Education, which is branch of the Norwegian Directorate for Education and Training. The focus of the project is to contribute to a better offer of rehabilitation for adults who have become strongly hearing impaired of deaf. The project is centralized at Briskeby School and Centre of Competence owned by the Norwegian Association of Hard of Hearing, HLF.

Since many of you were interested in that book and asked if it was possible to translate into English, the project manager Siri Skollerud asked the Directorate for Health and Social Affairs for money to carry out the translation. The answer was positive, and Briskeby now has 1000 copies for distribution to European Countries.

Send your orders to Briskeby and they will send you copies of the book.

The address is:

Briskeby Skole og Kompetansesenter
Ringeriksveien 77
3400 Lier
Norway
Phone: 00 47 32 22 65 00
Email: briskeby@statped.no

Subtitling for Hard of Hearing Children:

By Guus Coenen:

(the basic of this article is Guus Presentation at the Media for all conference in Portugal last fall)

Guus Coenen is chairman of FOSS the Dutch organization of parents with hearing impaired and speech-disordered children. And he is also board member of FEPEDA. The FOSS is also member of the Dutch steering group SOAP! = Subtitling On All Programs!

Subtitling are vital for hard of hearing children and more subtitling on children programmes is extremely important. So there is a need for more children television programmes to be subtitled. To enable young people who are hard of hearing to interact with their hearing peers, they require access to the same information and at the same time television is critical to this provision. We talk in Europe about 174,000 children as whole with severe hearing loss and a further 600,000 with mild hearing loss.

Hard of hearing children should be portrayed in a positive and realistic manner on television programs. Broadcasters and program makers should encourage stimulate the training of hard of hearing children and those who represent them. Subtitling for children's programs should be produced to minimum standards drawn-up and agreed by the broadcasting companies, regulatory bodies and organizations representing hard of hearing children and their families. Some of the priorities of effective subtitling are:

- allow adequate reading time;
- reflecting the spoken word with the same meaning and complexity relevant sound effects;
- placing subtitles sensibly in time and place;
- not making changes to the spoken word, construct subtitles which contain easily-read and commonly-used sentences in a tidy and sensible format.
- Particular regards should be given to the reading age of the intended audience;

Member countries should work towards agreed standards for the production, management and transmission of subtitles for hard of hearing children.

25 years Ménière committee NVVS, the Netherlands

Editor: Marcel Bobeldijk

Some years ago a TNE-doctor was a guestspeaker in a weekend organised by the dutch Ménière committee for Ménière-patients and their partners. He started his presentation with the following remark: " I don't like your kind of patients. I'm trained to help and assist persons who suffer from all kind of diseases, that's my profession. And for you, Ménière patients I can not (hardly) do anything. That's why I don't like you".

Some of the participants were not very pleased with his words. But with his remark he touched a very central element in the why/how of the position of the M.-patient.

How it started?

In the early eighties of the previous century a group of Ménière patients and some of their partners joined together in a weekend somewhere in the Netherlands. It was an initiative from the NVVS (then already existing for almost 75 years, the Dutch Assembly for the hard of hearing people). In the weekend the initiative was born to start a Ménière Committee. But during the first years of its existence there were all kinds of conflicts. And it took some years before the group was really established. Conflicts are (and will be) part and parcel of groups of hard of hearing people: communication and our drive to solve issues will create always new tension.

Where are we now?

In the Netherlands there are about 15.000 Menière patients (on a total population of 16.3 million). Only a part of those patients has been reached by our work. We are organising weekends for contact and exchange of information, for support, we have evenings with educational lectures. A lot is done through internet. More than 600 persons are on the website for exchange of experiences and information. We are publishing on Ménière disease. A very successful book was written some years ago with a compilation of experiences from a great number of patients. Information leaflets sometimes are on display in waiting rooms of ENT doctors or family doctors.

Hundred years NVVS.

We are operating in the framework of the NVVS. This year the NVVS is celebrating its 100th anniversary. A lot of activities are and will be organised this year.

Special attention from the Ménière point of view is given to entrance to all ENT doctors and their Assembly. We want to get to a situation where there will not be a repeat of what still a lot of Ménière patients is told at the end of the diagnosis: "So you have the Ménière disease, you have to learn to live with it "

We hope that a great majority of ENT doctors will refer to us, in order for the patient to get in contact and get the informations available. How his/her fellow travellers are struggling with the disease and sometimes find a solution.

Dreams.

Of course we are pressing for more research on this disrupting disease. On the one hand in the academic formal medical research. But on the other hand what we hope to achieve as well in the years to come is research – of high standard of course – on a more social-psychological level. What common features in their day-to-day life do M.-patients have? We want to reach more patients and their partners in order to exchange information, work on solutions, avoid the

difficulties many of us are (or have been) facing when confronted with this disease.

I hope to see some of you in Vancouver in order to exchange point of views how and what the best way forward will be.

Henk de Graaf , member of the dutch Menière committee NVVS
Email: 4degraaf@zonnet.nl

Work noise increases risk of hearing loss

If your daily workplace is noisy, you are at high risk for hearing loss and tinnitus

Daily exposure to excessive noise in the workplace is the primary factor in hearing loss in the working population. Years in a noisy job increases significantly the risk of serious hearing difficulties and tinnitus. The risk of serious hearing problems is more than doubled after five years in a noisy job.

Noise is a primary cause of hearing loss. I urge everybody to be aware of noise in their workplace. Look for ways to reduce the noise below the noise levels recommended by the authorities and protect your ears with earplugs or other hearing protection devices at all times, said Kim Ruberg, Secretary General of Hear-it AISBL, an international non-commercial organization.

The need for noise vigilance in the workplace is supported by data from around the world:

- As many as 95 percent of construction workers are exposed to high levels of noise on a daily basis.
- Among fire-fighters in Spain hearing loss is the second most common work related injury behind injuries from toxic chemical products exposure.
- One in two office workers in Germany is so severely affected by the noise level in the workplace that their work performance suffers.
- About 500,000 Austrians are exposed to potentially hazardous noise levels in their workplace.
- More than one in three Danish employees are exposed for more than one quarter of their working hours to noise levels so high that they must raise their voices to be heard over the noise.
- 30 percent of Sweden's farmers suffer from hearing loss
- Hearing damage tops the list of the most common work related injuries in Norway. Noise induced hearing damage comprise 58 percent of all work related injuries.
- In New Zealand the total compensation for noise induced hearing loss exceeds €20 million a year which is double that of five years ago. One in four claims from the agricultural sector is for noise-induced hearing loss.

Source: www.hear-it.org. Hear-it AISBL is an international non-profit and non-commercial organisation. The objective of Hear-it AISBL is to

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collect, process and circulate relevant information pertaining to hearing impairments and their human and socio-economic consequences
Further information: Secretary General, Mr. Kim Ruberg, +45 40 300 500, e-mail: hear-it@hear-it.org

Loud music is harmful for your ears, young people know this very well. Yet they don't want to turn the music of their MP3 down.

By the NVVS and translate Hanny Huigsloot

A report was published in the scientific magazine Journal of Pediatrics. The research was done by the Erasmus Medical Centre and TNO institute for applied physics. Hein Raat, who is a senior lecturer of youth welfare at the MC says that parents should not hesitate to discuss the slumbering danger of loud music for the hearing capacity.

Also paediatricians and youth nurses of the regional health centres play an important part at the prevention of noise damage caused by the extreme volume of MP3-players. Also the manufacturers of MP3 players have this responsibility. For instance they could install an indicator on their products, which shows when the volume will be too high at longterm use.

After having discussions with students it is shown that most of them turn up their mp3-player onto the maximum volume. In general they are aware of the risk, but they do not intend to turn the music down, because they assume they will not be affected by this.

Nearly all participants want to decide about the volume, most of the young people did not want to use hearing protectors. The 73 participants told the researchers that their parents hardly ever warned them about damage of their hearing. If the children show symptoms, after playing loud music, which is an early sign of (temporary) hearing damage, their parents even tried to reassure them.

For the time being, the researchers give the rule of thumb to restrict the volume to 60% of the maximum with hearing plugs and to 70% for use with headphones.

Toys may cause hearing loss of children

Toy torpedo, toy guns and other playthings as well as walkmans in order to hear music may involve irreversible loss of hearing of infants and young people. Close to the ear toy torpedo and toy guns induce a short-term noise of 120 dB and more. Such noisy sound may produce an immediately dying of a part of the inner ear. In this manner a well-intentioned present of a grand parent may initiate a lifelong hearing loss.

On 25th of January 2008 EU commissar Günter Verheugen announced „Toys are not products like anything else. Toys are designed for the most vulnerable consumer group“. Therefore it is not allowed to make a compromise for this group. They need specific protection.

The European Commission intends to revise the EU directive for toys. Some US products imported from China exceeded the damage threshold of lead. Verheugen gave a presentation of an amended European toys directive draft which is going to be discussed by the European Government and the European Council of Ministers.

Deutscher Schwerhörigenbund e.V. is pleased about the utmost concern of the European Commission to revise the European toys directive. But the draft includes no specifications for the prevention of noise and the protection of children in this matter so far. The acoustic organ is sensitive. Noise may make an irreversible impact, e.g. by Mp3-Player and toy gun with percussion caps.

Therefore Deutscher Schwerhörigenbund e.V. requires that the European toys directive has to contain specifications for protection of good hearing. It should be a guideline for manufacture of toys.

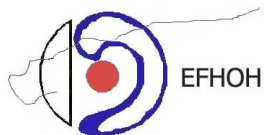
Contact person: Detlev Schilling, Business manager Phone: +49 30 47 54 11 14 Email: dsb@schwerhoerigen-netz.de

History of the NVVS II

Before the WO II we had no internet to find the important information about hard of hearing and the organisation for hard of hearing. The Dutch Hard of hearing organisation NVVS decided to make a small yearbook. This yearbook gave lot of information about the organisation and other important subjects for hard of hearing. The NVVS was also very active in the beginning in founding schools. In 1914 the schools in The Hague and Amsterdam were the first schools in Holland for the hard of hearing youth.

To support these schools the NVVS organised all kind of activities. One of these activities was the 'flower day'. All local clubs were selling bulbs and flowers to support the hard of hearing children. The money they had collected in this way was given to the Dr. Johan Sasse Fonds. This foundation was responsible for supporting the hard of hearing schools and making it possible for the children to go to school. In many cases the foundation also supported the child and his family. They also tried to find foster parents, where the children from the countryside could stay during the week.

The NVVS was also one of the founders of the first audiological centre in Holland. The so called Central institute was the place to visit for the hard of hearing. There they could find all kinds of hearing instruments to try.



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When they found the hearing aid they liked, people could go to a hearing aid shop to buy one. At the moment the electric hearing aids came up, this Central Institute was changed into a audiological Centre and became a professional organisation.

The NVVS has had a big influence on all kind of developments in the hard of hearing world in Holland. Nowadays the organisation still has its influence and it is becoming stronger and stronger.

Kees Twilt

CZECH NATIONAL DISABILITY COUNCIL

In the frame of the project **'WITHOUT BARRIERS'**

Would like to invite you to the

4th International Conference 'HOUSING WITHOUT BARRIERS'

21st – 22nd May 2008, Congress centre Prague (Czech Republic)

The frame project WITHOUT BARRIERS' has been launched in 2005 by Czech National Disability Council and ABF Corp.,. The project is arranged as a cycle of conferences with international participation. The expert background is the European Concept for Accessibility – a concept on awareness raising for expert from the fields of design, engineering and construction, the concept of friendly environment for all Citizen with no distinction of their mobility limitation. Expert conferences 'WITHOUT BARRIERS' shall contribute to achieving of this concept's objectives.

'WITHOUT BARRIERS' conferences has been launched in 2005 by the conference 'TRANSPORT WITHOUT BARRIERS' with the participation of more than 100 experts a participants from 6 EU countries. The theme of the conference was decided due to the fact that the transport accessibility is among the first steps to overall accessibility. 2nd conference 'CITY WITHOUT BARRIERS' was organized in May 2006, with the theme of removing barriers and accessible environment in towns and cities. 3rd conference has the title 'ACTIVELY WITHOUT BARRIERS' organized in May 2007 and targeted at leisure time – sport, culture and travelling without barriers.

Czech National Disability Council would like to invite you to take a part in the conference and, with regard to your activities' objectives and experiences in this respective field also kindly ask you for your contribution to the conference.

We expect about 20 – 25 presentations and 3 workshops in this year's conference. As you can see from the title, we would like to aim this conference to architecture and design. Partial Themes would be – Rural residential zone, town residential area, equipment of accessible apartments and one session devoted to news and interesting issues which cannot be included to the above-mentioned sessions.

All relevant and updated information will be presented on: www.bez-barier.cz

We would like to welcome about 120 – 150 participants in our conference. The official language of the conference will be Czech and English.

The social evening will be organized in the frame of the conference at Zofin Hall in Prague.

The conference will be organized under the auspices of:

Mr Mirek Topolánek, Czech Prime Minister
Mr Pavel Bem, Prague Mayor
Mrs Džamila Stehliková, the Minister of the Government CR

Thank you for your time and answer in advance. We hope you find the conference interesting and helpful in promotion of accessibility and social integration of persons with disabilities.

For further information, please contact **Ms. Veronika Purova, CNDC, Partyzánska 1/7, 170 00 Prague 7, Czech Republic, tel: +420 266 753 423, +420 736 751 215, fax: +420 266 753 420, e-mail: v.purova@nrzp.cz**

TREATMENT OF TINNITUS:

BY HANNIE HUIGSLoot

Tinnitus can be very frustrating, but it does not create a threat for one's health. In some cases it is caused by a specific disease, such as Meniere syndrome, otosclerosis or a chronic middle ear infection. After the disease has been treated, often the tinnitus will stop spontaneously. This can be the case if a little earwax was the cause of it.

Often the cause is hard to be traced and even if so, this does not imply that treatment is possible or effective.

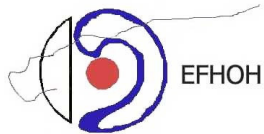
If the tinnitus patient has tinnitus all of a sudden, it is strongly recommended that he sees his GP. If he finds a reason to refer the patient to a specialist, he will send him to the hospital or an audiological centre.

In Germany for instance acute tinnitus is dealt with completely different from the Netherlands. There it is treated as an emergency and often within 24 hours, the patient with such acute tinnitus is sent to the specialist.

In Germany a special oxygen therapy is applied regularly for treatment. There is no scientific proof yet about its effect. But in the 'Hor-akustik' (hearing acoustics) magazine in March 2001 there was a report on very good results at the application of this therapy. This therapy seems to be very appropriate when its applied very soon after the forming of the tinnitus. special oxygen therapy for tinnitus. The members of the tinnitus and hyperacusis committee of the NVVS are working hard towards the recognition of this treatment and they express the wish to obtain more research into tinnitus and a better registration of the effects of this therapy.

In Germany often medicine is prescribed, to cure illness. Yet again in The Netherlands the professionals are very cautious. Dr. Ganz calls this therapy in the book 'Living with tinnitus' (originally a German book) a fashion-therapy. Also he indicates that there is little proof for other medication.

There is very little one can do about tinnitus, so it is very important that the patient conquers the tinnitus mentally. The patient should never accept the advice: 'you will have to learn to live with it', but he



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should look out for a specialized consultant who can advise him how to learn to live with it. An audiological centre is the right place for this. A psychologist who has specialized in tinnitus, cooperating with an Ear Nose Throat specialist would be the right job. Sometimes masking is used for treatment, and recently a new positive therapy is the Tinnitus rehabilitation Therapy. This is a therapy where the patient can learn how to cope with tinnitus.

With tinnitus it is very advisable to avoid stressful situations. Also caffeine (coffee, tea), tobacco and other stimulants should be used in moderation. Also it may be useful to turn on some music in the background, so that the tinnitus in one's own ears will be less loud and disturbing.

Article's needed for the next EFHOH newsletter

You can send articles to the editor Marcel Bobeldijk:
Marbob32@hotmail.com

The newsletter is witching several short stories; the article should not exceed one page.

Deadline for the next newsletters in 2008 are:

1 of September 2008

1 of November 2008

if you need more time, contact Marcel.

Let's make a good newsletter together!