

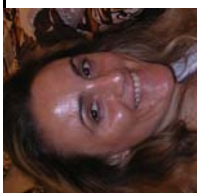


Ifhohyp News March 2003

IMPORTANT ANNOUNCEMENT !

**New Study Session
Strasbourg (France)
12-19 October 2003
More details at page 6**

**The Newsletter of the
International Federation Hard of Hearing
Youth People**



GENDEAF NEWS

IFHOHYP is involved in GENetic DEAFness (GENDEAF) project as member to produce a Bulletin of the European network on GENetic DEAFness.

It has been published the first issue of the GenDeaf project bulletin. Its main purpose is to inform patient organisations, patients, their relatives and friends about this new European initiative to *raise awareness of the causes of* inherited deafness and allied syndromes with the ultimate aim *of constructing* a basis for future treatments and improved rehabilitation.

Interested organisations may use this newsletter fully or partly to inform their members about the project. But we would like the newsletter to be a two-way exchange, and we invite readers to interact with the researchers involved in the project by sending questions and remarks to the editorial board (cfasser@e-link.ch) or directly to the project (www.gendeaf.org).

The main objective of the present Bulletin is to create a **pilot network** between associations and researchers for the exchange of information with regard to advances in research and also patients' needs and expectations. It is essential for patients and their families to have information so that they know about research developments and can therefore contribute to it actively. Vice versa, scientific developments and information are mostly passed on in scientific journals and conferences, and reach patients and their families, who may have a direct interest in sharing such information, much later. *The aim of the network is to bring patients, families and their associations closer to research in this field as well as researchers closer to patients' need for information.*

Gen deaf News is targeted at patients, their families and medical personnel involved in genetical hearing impairment. It is written in lay language and, besides English, is also translated into Swedish, French, German and Italian. GENDEAF NEWS is published on the Internet but Associations and patients' support groups that would like to include it in their journal or publications may do so, with the agreement of the Editorial Board, citing the source of information. The network objective is to inspire such initiatives throughout Europe. The consortium will collaborate with any other organisation which requesting authorisation for translating it into other languages.

GENDEAF NEWS will comprise 6 sections:

Section 1: "RESEARCH CORNER" (by researchers): monographic chapters on topics of general interest. These monographic papers should be used by ENT, audiologists or geneticists to improve communication giving information on a particular topic;

Section 2: "LATEST NEWS" (by researchers): updating of the last six months both in molecular biology and in clinical genetics: Short, very clear summaries of the most relevant news, written in a non specialist, simple language;

Section 3: "ASSOCIATION CORNER" (by associations): social aspects, laws, activities and initiatives etc.;

Section 4: "MISCELLANEOUS" (by associations): Miscellaneous issues;

Section 5: "LETTERS" (by patients/families): questions/letters submitted by patients, families, associations' members etc;

Section 6: "MEETINGS AND EVENTS".

THE GENDEAF PROJECT: AN OVERVIEW

European network on GENetic DEAFness: pathogeni

The network brings together a multidisciplinary community of clinicians, researchers and hearing impaired support groups with complementary expertise. The aim is to promote a balanced dialogue between these groups. The network will focus on the classes of hearing impairment with the highest prevalence and social impact. This will result in clinical applications in the near future.

Aims of the project

The project will advance the state of the art in this field in particular for the following items:

- 1) collecting data on the prevalence of mutations in the CX26 gene which is the most frequent disorder occurring in non-syndromic neurosensory hearing impairment (NSSNHI) in various European populations. This will help direct priorities for the strategy of development of routine molecular testing in individuals sporadically affected with NSSNHI improving diagnostic protocols and rehabilitation strategies;
- 2) providing tools for early diagnosis of Usher syndrome, which is now often only made late in life (young adulthood). This late diagnosis has wide implications for those affected and their families. Since this syndrome is progressive rehabilitation in terms of communication and education becomes extremely important once the diagnosis is made;
- 3) creating pathological models of aminoglycoside ototoxicity and other types of mitochondrial deafness. This work will involve an original and interdisciplinary approach linking medical and behavioural geneticists with cell biologists and biochemists, and using a set of different model organisms each of which has distinct potential advantages. The creation of pathological models of this type provides an important bridge to pharmaceutical R&D and to eventual commercialisation of diagnostic, prognostic and therapeutic discoveries;
- 4) providing tools for identifying possible specific clinical correlates to different disorders in order to contribute to the design of more detailed and focused clinical protocols for facilitating an earlier and more accurate diagnosis of non syndromic hearing disorders;
- 5) acquiring more knowledge on the specific psychosocial consequences of genetic hearing impairment on individuals and those around them. This will play a growing role in providing appropriate counselling. In fact, in congenital hearing impairment there is often a reaction of denial amongst parents of hearing impaired children with genetic aetiology. They seek to attribute the cause of the hearing loss to environmental or infectious factors. A similar dichotomy may occur with late-onset genetic hearing impairment. While some individuals may see that other family members have led a successful life despite their genetic hearing impairment others may see that it has led to a devastation of careers. The fact of having individuals in close family proximity who have coped with this, may also have an influence on the acceptance and reassurance which people have.
- 6) **involvement of patients' organisations. This will be a unique opportunity to bring together patients and researchers in order to facilitate co-ordination of activities and transfer of knowledge and co-operation, ensuring that our society is informed of the potential and benefits of scientific and technical advances due to research in the field. This will benefit both patients, through their organisations, who will be connected to a network of the major experts in this field which may give answers and updated information regarding the disorder that affects them and researchers who will probably find co-operation from patients who can give voice to their points of view on issues which concern them. European benefits will be gained by optimising scientific networking, co-ordination, exploitation and dissemination. Furthermore, this will be an opportunity for patients' organisations to collaborate and liaise on common objectives at a European level.**

This is the *first attempt* to link the work of patients' organisations and scientific research in order to spread information on genetic hearing impairment and deafblindness not only at a scientific level but also at a level understandable to the patients, families and medical personnel involved in this field. The main outcome and purpose of this group will be establishing a network and publishing the present Bulletin on the Internet, translated into

five European languages and in a form accessible to blind and visually impaired people. All members of the project will contribute to the Bulletin. **There will be published three issues per year (2003 and 2004 – the whole duration of this project), so please check the website and download the upcoming bulletins regularly. Contribute to its diffusion as well!**

ANNOUNCEMENTS:

The group **Psychosocial consequences of genetic hearing impairment study group** asks to the families and patients the following contribution:

1. If you as well as other members of your family (parents, brothers and sisters, children) have hearing problems, we would like to hear from you.
2. Please let us know of any ways that having other people in you family with hearing problems has affected your reaction to your own hearing problems. Write down as many effects as you can think of.
3. Please also let us know whether you would be agreeable to answering any other questions about your hearing problems and their consequences.

Please e-mail us at StephensD@cf.ac.uk

MEETINGS

1st **general meeting of the Gendearf Project** - Milano Italy, 8-11 May, 2003

The editorial Board is composed by the following people and their organizations:

Chief Editor: Christina Fasser (RETINA International, Zurich) - CH

Board: Patrizia Ceccarani (Lega del Filo D'Oro ONLUS, Osimo) -I

Manuela Mazzoli (U.O.A. Otochirurgia, Padova) - I

Vanessa Migliosi (International Federation of Hard of Hearing Young People, Trento) - I

Vibeke Leth (Daniish Association for Cochlear Implanted Children, Enskede) - S

Don't forget NEXT MEETINGS !

-IFHOHYP AGM Valencia, Spain, 17-21 April 2003.

For further news please contact Maria Lopez
(logarma6@hotmail.com)

- Intercultural learning and human rights education in the Mediterranean area. (20-28 May 2003) European Youth Center Budapest.

-Training Course on Management of Non-governmental Youth Organisations (03 – 14 June 2003) European Youth Centre Budapest.

-IFHOHYP Summercamp, Netherlands, 27 July– 8 August 2003. (see www.ifhohyp.dk or www.shjo.nl)

NEWS FROM THE WORLD

How to subtitle a movie....without subtitles on screen

One of the biggest problems for hard-of hearing people is comprehension of movies at cinema or theaters. In fact, many cinemas refuse to subtitle (or “caption”) movies because many hearing people hate subtitle on screen. So a new technology has been discovered, the “Rear Window Captioning”.

The Rear Window Captioning System is an innovative technology that makes it possible for exhibitors to provide captions for those who need or desire them without displaying them to the entire audience, and without the need for special prints or separate screenings. The Rear Window Captioning displays reversed captions on a light-emitting diode (LED) text display which is mounted in the rear of a theater. Patrons use transparent acrylic panels attached to their seats to reflect the captions so that they appear superimposed on or beneath the movie screen. The reflective panels are portable and adjustable, enabling the caption user to sit anywhere in the theater.

There are some differences from “open captions” and “closed captions”: Open captions are similar to subtitles. They are "burned" onto the film and visible to everyone in the theater. To provide open captions, it is necessary for studios to create and for exhibitors to obtain a special print of the film. Open-captioned films are generally presented at special screenings.

The Rear Window system is a way of providing closed captions. The captions are not on the film itself, so there is no need for a special print. The captions are on a floppy disk or CD that plays in synchronization with the film. The captions are visible (via a reflector) to only those patrons who choose to see them. The captions are available during regular scheduled presentations, for as long as the film plays in the theater.

The Rear Window technology started several months ago in USA, and it has got a good success. Since now, many cinema or theaters in the main cities are equipped with the Rear Window technology, with no supplementary ticket cost for moviegoers.



How the Rear Window captioning work.
Courtesy of WGBH and Rufus Butler Seder

Article written by Andrea Pietrini (Italy)





Report from the Official launching ceremony of the European Year of People with Disabilities (Athens, 26/1/2003)

The official European opening ceremony for the European Year of People with Disabilities took place on Sunday 26 January 2003 in Athens. This event has been jointly organised by the Greek authorities and the European Commission, with the support of the European Disability Forum and the Greek Confederation of Disabled People.

The famous Megaron Concert Hall in Athens was chosen for the venue. The ceremony which lasted for approximately three hours was very lively, varied and moving. Key EU and national politicians, Greek Minister of Social Affairs, Commissioner Diamantopoulou, Vice-President of the European Parliament, Mr. Podesta, EDF President, Yannis Vardakastanis, started the ceremony with key speeches. As well as other politicians, European Commissioner of Social Affairs Anna Diamantopoulou, supported the mainstreaming of disability in all EU and national policies. The Ceremony was also honoured with the presence of the President of the Greek Republic.

The speeches were followed by several cultural acts, performed by disabled artists and musicians. Six persons, five with disabilities and one parent of a disabled child, addressed the audience with sincere testimonies. The event ended with a musical finale where famous singers Ms. Maria Faratouri and Mr. Gilbert Montagné (as ambassador of the European Year in France) performed.

It was especially moving and exciting that in a first row, sign language interpreter started interpreting the song with all her body for a relatively small group of deaf guests sitting in front of her. Then – a very good visibility for deafness – the interpreter was shown on a large screen passionately dancing and singing the song with her hands, though this sign-singing performance on screen seemed to be not planned in advance. Text of the song could be read on screen as well, which made it easier for deaf and hard of hearing guests to follow it.

By the way, if any wishes could be made for future organization of such ceremonies, I would ask to not forget about hard of hearing people! We need induction loop systems installed at such disability events – sometimes headphones' volume is low for us and sounds can not be distinguished.

About 1500 guests were invited to the opening ceremony - representatives of European and international organisations of people with disabilities, Ministers from all EU Member States (including Norway and Iceland) as well as Ministers from EU accession countries, representatives of EU Institutions and other key stakeholders from Greece and the rest of Europe were present at the ceremony. Of the representatives from hard of hearing people there were Mar-

cel Bobeldijk, Holland (EFHOH and former active volunteer in IFHOHYP) and myself. Silvana Baroni represented FEPEDA (European Federation of Parents of Hearing Impaired Children), and there were more representatives from organizations of the deaf. However, this event was a bit difficult for contact-making because guests were not given name tags.

The aim was to transmit all over Europe this simple message: people with disabilities have the right to be accepted and to participate fully in society.

The opening ceremony also marked the starting point of the European Year of People with Disabilities march. The march, which will be spearheaded by the specially designed EYPD Bus, will travel across Greece before continuing across all the European Union Member States.

To reinforce the campaigning effect of this march, disability communities in every EU country will organise events to build on the march passage through their cities, towns and villages. These will include festivals, debates, partnerships, conferences, parties, lobbying and more - whatever local people with disabilities decide is the best way to get their message across.

And then we will see what EYPD 2003 brought to us. My personal hope is that disability activities will be actively run, have tremendous impact and get publicity not only in the European Union states (as EU bodies are the main initiators of EYPD) but also in other countries of the European region - and that all high-level disability resolutions that can be accepted this year, will not merely remain on paper. Let's contribute to EYPD!

Last, we will be glad if you could tell about your organization's activities run during this special year, in IFHOHYP Newsletter. You are welcome to write to us!



NEW IFHOHYP STUDY SESSION IN EUROPEAN YOUTH CENTRE, STRASBOURG

"Building communication for hard of hearing young people: breaking barriers and stereotypes", European Youth Centre, Strasbourg, 12-19 October 2003.

Communication is one of the major problems facing youth groups and youth organizations in their work, and it is especially difficult for hard of hearing youth. The lack of communication skills and self-confidence resulting from hearing impairment makes hard of hearing people less visible on a scale of local and international youth work; it hampers the efficacy of hard of hearing youth work in NGO structures: in addressing the needs towards various bodies and authorities, in lobbying, interacting with governmental structures - and simply in business talks with donors, project officers, politicians and other key figures supporting NGO activities. On the other hand, people often don't know how to deal and communicate with the hard of hearing - this may result in frustration, intolerance and conflict for both hearing-disabled and non-disabled community members.

Article written by Karina Chupina, Ifhohyp vice-president



In the age of information it is necessary to keep pace with political and social developments. Keeping up with changes in reality is difficult for hard of hearing youth who lack access to information, communication and thus to institutions and society processes. Majority of hard of hearing people turns out to become outsiders in society life. In turn, society has formed the stereotype that hard of hearing minority is complacent with life in their own secluded environment, that sign language and a number of privileges compensate for their disability - this stereotype is equally common in countries of different level of economic, cultural, ethnic and social development.

The main aims of the study session are to increase communication skills of hard of hearing youths for use in their organizations and national/international youth work - as well as for their integration into the society; to develop communication skills from personal level to the level of organization's internal and external communication; to improve the communication between IFHOHYP members and increase involvement of new young leaders from member and new non-member countries.

The overall long-term aim of the IFHOHYP study session and events in the 2003 European Year of People with Disabilities is to increase participation of hard of hearing youths in civil society and empower them in informing public of their needs and disability.

In light of this, some of the objectives are:

- To provide participants with an opportunity to assess their communication needs and to explore variety of communication methods
- To enable participants to define rules and practices of communication in relation to themselves, their organizations and the public
- To enable participants to run an exchange of ideas and experiences in an intercultural learning setting
- To help participants in building self-confidence and improving competences in addressing disability concerns to the public

Subjects to be covered in the Study session are:

- Communication is the Dialogue: from personal to organizational and intercultural level
- Hearing disability in the context of Intercultural learning
- How to learn from different realities and different experiences of the Western and Eastern European countries; exchange of good practices.
- Communication and interaction problems: coping with conflicts
- PR and communication tools
- Foreign language as a tool for intercultural learning and problems in foreign language study for hard of hearing youth
- Producing research and other materials for the follow-up to the study session

(Please note: Study session aims and objectives will be further adjusted at the study session Preparatory meetings.)

Preliminary technical information:

Dates and participants' profile:

Study session will take place in the European Youth Centre of the Council of Europe, in Strasbourg, on October 12-19, 2003. About 30-35 participants from different (mostly European) organizations of hard of hearing young people will be selected on the basis of application forms which will be sent out by Preparatory team in summer. Participants should be hard of hearing young people aged from 18 to 30 who are active volunteers/workers in non-governmental organizations from all over Europe, are running/intend to run projects on awareness-raising of the society and authorities about the needs of hard of hearing youth. Exception in regard to age limit and hearing loss can be made for a certain number of applicants.

This year we also hope to invite more participants from non-European countries and give them chance to learn.

Study session Preparatory team:

This year, study session team consists of Karina Chupina, course director (Russia), Jennie Westh (Denmark), Markku Kunnas (Finland), Candy Villaescuza Pedroche (Spain). One of the educational advisors or external trainers of the European Youth Centre will be working with the team to ensure quality of the study session.

Working language:

Working language of IFHOHYP study sessions is usually English.

Travel reimbursement:

Travel expenses of the participants will be reimbursed on spot in European Youth Centre or through bank transfer. Participants will have to provide EYC with proof of their travel expenses (receipts, invoices) and ticket copies.

Cost of living for young workers:

The EYC operates a system of compensation for living costs of young workers and young people who are unemployed. The system is designed to avoid financial losses for young workers and unemployed people who are obliged to take an un-paid leave or who lose their benefits due to participation in the study session. More information and forms will be sent later to all organizations.

Participation fee:

Enrolment fee of 43 Euro will be deducted by European Youth Centre from the refund of travel expenses of each participant where these amount to a larger sum.

Facilities and equipment:

Accommodation and meals will be provided by the European Youth Centre throughout all week. Plenary room where IFHOHYP study sessions have been held since 1994, is equipped with induction loop system which transmits sounds directly to hearing aids and is of great help. As usual during IFHOHYP study sessions, palantype service should be provided – a fantastic text-to-screen tool which enables participants to simultaneously read all plenary discussions on a big screen.

Further details and application forms will be sent out in summer. Should you have any questions regarding the study session, please feel free to contact Karina Chupina (karinac@hotbox.ru) and Jennie Westh (jennie@post9.tele.dk).

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