Ifhohyp News

The international federation of hard-of-hearing young people newsmagazine

Autumn 2005 edition
Hi people! Here I am to explain you all about the beautiful SummerCamp 2005 in Czech Republic.

I would want to write a lot about SC, but the “boss” of the newsletter committee told me: please not too long. Then: ooooooookeeeeeeey, I will try to make a summary.

First day (6th August) all participants met in Prague. Gordon, a very funny leader, picked up each participant in the airport, bus station or wherever. People were arriving to the hostel and we knew each other. For people who was in Holland in 2003 was very easy to learn the names, since the 50% of participants were the same. It was very nice to meet people again, and meet new people, of course.

SC started with a beautiful welcome dinner, with a lot of food and drinks. And the leaders introduced themselves: Simon, Martin, Lenka, Iva, Gordon, Monika, Radka, Tereza and Frantisek. About the participants, we were from many countries: Spain, Holland, Russia, Italy, Sweden, Lithuania, Germany, and Switzerland.

The first day, we made a sightseeing of Prague in a special way: it was a game in groups with questions about buildings, squares, different places of the city. It was funny, but the weather was crazy: raining, cold, hot, sun. I was opening umbrella, closing, opening, dressing with jacket, undressing… the whole day.

In the next day we went by bus to the wonderful hostel in Strelske Hostice.

After dinner we celebrated the Opening of the Olympic Games. It was emotional, each country, with its flag, marched around the hostel and we met in a place with sounds of drums while each country shouted: Spaaain, Hoooooollaand, Ruuuuuussiiia…

After taking photos, leaders communicated the members of each group for the Olympic Games: blue, black, yellow, red and green. Each team had to show its effort and sport spirit during “hard” 2 weeks.

The Olympic Games started with a football match, 5 teams playing at the same time, in the same pitch with 5 goals. It was a crazy game, but very funny with 5 balls!!! Later, games continued: “races”, frisbee.. Later each team had to design the mascot using recycled bottles, boxes, papers… There were very original mascots.

Olympic Games continued with Frisbee and volleyball tournaments. Frisbee was like rugby game, in a big pitch where participants had to run, run and run a lot. In the afternoon there was a workshop: handcrafting masks, it was a very relax afternoon because
while your partner made your mask, you was laid down. I heard that one participant was sleeping and making some strange noises (haha).

We visited the Budweiser Beer factory in Ceske Budejovice too, where everyday they make and prepare millions of litres of beer. Later we went to a beautiful castle in Cesky Krumlov where the guide explained to us the story of this building, families who lived there, costumes that they had, it was an interesting visit.

One day we had climbing, canoeing and finally painting the masks. In the evening leaders worked a lot as drivers to go to the disco, where some people drank a little more than normal... Some people instead, in the restaurant, ate something that they didn’t want (menu was only in Czech and waiters couldn’t speak English) and maybe you wanted chips but they served fish, ha-ha. Some boys were dazzled because of the beautiful stripper girl in the disco... it was a funny evening.

Sunday was free, so participants could rest and recover for next sport days. After dinner some Spanish people played and danced at rhythm of Spanish music.

One evening we had theatre, participants of each country had to show everybody how people celebrate a wedding in their countries. It was nice; some of these representations were very funny. And we learnt about different cultures.

About at the end of Summercamp, we had to play the last game of the Olympic Games and then we got the final results. This last game was a Quiz: questions about Summercamp, leaders, participants, activities...It was very funny, in some questions we had to recognize some photos, who was in the picture or the owner of a shoe for example...haha. After that leaders showed us the results of Olympic Games, and the winner was the Black Team. Each team received the medals, certificate, and a prize.

Later, leaders organize BBQ, and one of them showed the way for arriving to the BBQ place in a very nice way: with small candles.

At the end of the evening, people met in the bar of the hostel drinking the cheap beer and taking photos with everybody.

And last day arrived, we came back to Prague and we had to say good bye, there were a lot of tears, kisses, hugs... but with the hope to meet next summercamp in Spain.

Summercamp was a very nice experience, with a very good organization of the activities, in spite of the bad weather, with a very good company of participants and leaders (always smiling). For me it was very wonderful time. I’d like to thank leaders a lot because they worked a lot.

THANK YOU VERY MUCH LEADERS!!! And thank participants for participating in all activated, having good company... I hope you in Summercamp 2006.

Maria Lopez Garcia
Education of the deaf and hard of hearing children in Russia starts from a special kindergarten. There are 99 such kindergartens in Russia. The basis of education for children is language learning, understanding of speech, mastering speech. Children usually study from 2 to 7 years old, sometimes until the age of 8. Groups with multiple disabilities are also possible, for example there can be deaf children with mental disability. There is the only centre for blind and deaf children in Russia which is located under Moscow. This centre is fully financed by the state, children can be left overnight to sleep so that parents do not have to overcome long distances daily in order to get their children to the centre.

All kindergartens are state institutions and are free for parents regardless of parents’ income. There is a conventional division of the kindergartens “for hard of hearing” and “for deaf”, but in reality the composition of a kindergarten depends on intellectual abilities of children, readiness of parents to educate and train their children as much as possible, and on the proximity of a kindergarten from a child’s home.

So-called medical-social-pedagogy commission can give an assignment to enter mainstream/regular and logopaedics kindergartens or groups accordingly with the wish of parents. In large cities one can find rehabilitation centres for the children with hearing loss that are attended by hard of hearing kids from regular kindergartens and kids from home. There are also children’s homes for deaf kids, orphans or abandoned kids; foreigners adopt such kids with pleasure.

Everywhere (except for regular kindergartens) speech therapists work with children since the earliest age possible – speech therapists or “surdopedagogues” work on speech and hearing development while educators work on social adaptation in groups of 5-8 kids, using game approaches. Same work is also done individually. By the age of 4-5 kids can read, they start speaking, later counting. Note that the role of music and arts is crucial in overall development of HOH kids: musical classes, dances, rhythmics, even singing are imperative. Sign language is not taught, it is picked up by kids from their parents and/or from each other. As a result, there is a sign language of its own kind in every different region or even in dif-
ferent schools. Oftentimes even adults cannot understand each other and TV news readers’ reference sign language interpretation. It is just a short time ago that the dictionaries, videotapes and CD-Roms with sign language appeared on sale.

Guess what is one of the best ways to develop listening and hearing, expand the vocabulary, improve literacy, feeling of rhythm and plasticity? Sign language singing - performed by hard of hearing kids and young people. In the last years contests and festivals on sign language singing “Singing Hands” acquired a lot of popularity. Funding for such contests is normally allotted by the Council of Ministers of Nordic Countries. Interestingly enough, such performances are thoroughly enjoyed by the mainstream public.

Our organisation suggested, as an experiment, the participation of a hard of hearing sign language performer in the mainstream festival, in nomination “solo singer”. There was a storm of applause. By the way, such performances are a good way to raise positive image of hard of hearing.

Accordingly with the commission’s conclusions, children are directed to different schools that correspond with their level of preparation, level of hearing loss, skills, abilities, including financial abilities… When speaking of financial abilities, I mean mainly the case when kids study in mainstream school - in Russia, in contrast to many countries, speech therapists do not regularly attend hard of hearing/deaf alumni of mainstream kindergartens and schools. To continue developing speech, students’ families should pay for the speech therapist’s courses.

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Personal consultants/advisors for disabled students, like in the United States or some European mainstream high schools, who have regular appointments with disabled pupil and help him to get through the study and social process, are not common in Russia so far. In a few mainstream schools they decided to run experiments on accompanying several pupils by speech therapist who sometimes can also perform in a role of a personal advisor.

Some hard of hearing pupils managed to stay in mainstream school for 3 years, others hardly managed to hold out the stress until 7-8 grade. They entered specialised school for deaf/hard of hearing instead, where they feel more secure, relaxed and confident. These were the best prepared hard of hearing kids by the way. So why change? It became less and less psychologically comfortable for them to study among hearing pupils especially as the study programme got more intense and difficult (in Russian schools, a load of 15-19 subjects per year is not a joke). Even with the support of administration and parents, for some pupils study and environment got tougher to endure with every year – especially so in the teenage period.

It is even more difficult for youths with big hearing loss to be the only hard of hearing pupils in regular school. After many thoughts and reluctance, many pupils in high school classes changed their school for a special school. They quickly mastered sign language and got involved in social life of a school. Just few hard of hearing completely graduate from mainstream schools; even lesser number can fully integrate in society. Quite many of such mainstream graduates do not want to identify themselves as hard of hearing or deaf – sometimes they conceal their concerns even from themselves.

In the recent years the practice of school education from home became widespread as well and can be carried out upon the wish of parents.
After three years, the Gendeaf project has reached its end and the Final Meeting of the European Thematic Network on GENetic DEAFness took place in Caserta from 17 to 19 March 2005.

Vanessa Migliosi, as IFHOHYP responsible for the Gendeaf Project, and Maria Lopez Garcia, as IFHOHYP Vice-president, participated to the final meeting.

The title of this meeting was: “Genes, Hearing and Deafness from molecular diagnosis to clinical practice” and the program included round tables, teaching presentations, open lectures and poster presentations.

250 Italian and foreign specialists took part in discussing important topics like molecular biology research (genotype-phenotype, mitochondria, connexin 26), clinical practice, the social and communication impact of genetic disorders, cochlear implants and deafness with and without syndromes.

The objectives of this three year project were:

1) To collect data on the prevalence of mutations in the CX26 gene in individuals with non-syndromic hearing impairment (NSSNHI) from various European populations;

2) To measure the frequency and range of mutations in myosin VII A and usherin in individuals with Usher syndrome;

3) To develop exploitable pathogenic models of aminoglycoside ototoxicity and other
forms of mitochondrial deafness;
4) To establish phenotypic criteria for recognising subgroups of non-syndromic hearing impairment;
5) To define the specific psychosocial impact of genetic hearing impairment on affected individuals and their families;
6) To facilitate communication between the research and hearing impaired communities (patients, families and their associations) through the publication of the “Gendeaf News” bulletin.

The point sixth is the more innovative, because it has represented the first attempt to create a pilot network between associations and researcher. Its main objective is to involve directly patients’ organisations to which pass on information (through the bulletin) and to give voice to their point of view on issues which concern them. Scientific publications are not easily understandable for non-specialists and journalistic reviews are often too general and out-dated. This has been a unique opportunity to bring closer patients and researchers for the exchange of information with regard to advances in research and also patients' needs and expectations. In the last bulletin, the experts have published the most relevant parts of some of the papers presented during the final meeting. I invite you to read last news! You can browse in the GenDeaf website (www.gendeaf.org) to find all bulletins published in some European languages and up-to-dated information. In the last bulletin I wrote a scientific article about the last developments and discoveries on genetics of deafness.

From both a personal and professional point of view, I hope that the network of cooperation and contact we have established can continue in the future.

Vanessa Migliosi
Biologist and GenDeaf project responsible on behalf of IFHOHYP

-Want to read the IFHOH magazine? Go to www.ifhoh.org/ifhohefhoh.htm
-Activity of institutions at: www.coe.int.
-Next Summercamp? Summercamp2006 will be held on August in Spain.
-Next Ifhohyp Study Session will be probably held in the first half of 2006.
……..and stay tuned at www.ifhohyp.org for more news.
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WEBPAGE
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The mission of IFHOHYP

IFHOHYP is committed to promoting equal rights for hard of hearing young people at all levels of the community. We believe that hard of hearing young people have the right to a good education, freedom of choice, the right to equal treatment at labour market, necessary support and technical aids they need to assimilate to life in the hearing community.

To encourage a better understanding of hard of hearing young people and their problems among the general public.

To defend the interests of hard of hearing young people and express them towards international bodies.

To serve as a platform for cooperation and exchange of information between organizations of hard of hearing youth.

To establish links with organizations of and for hearing-impaired people, improve communication and cultural interchange between all hard of hearing young people worldwide; to receive new information from other international youth or disability organizations and provide with it hard of hearing youths in different countries.

To collect and make available all information on different aspects of hearing loss, on technical advances, facilities and assistive listening devices for hard of hearing people.