



News Letter

1/2020

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Greetings from the President

Dear Friends,

I hope you are all well and healthy! The first months this year have been very exceptional as the COVID19 pandemic has affected our lives in many ways all over Europe. In this challenging situation it is very important to remember and to protect the rights of the hearing-impaired children, young people and their families – you will find FEPEDA's position paper on this topic in this issue. Please feel free to share it in your own channels.

Despite the challenging circumstances our work continues. This year is a very special one for us as we are celebrating our 30th anniversary! Please find our new special "30th anniversary" logo above. We have many activities planned for this year and all these are requiring your active participation. The Bureau and the Management Committee have been working with several projects - in this Newsletter you will find more information on our Photo Campaign as part of our 30-year-celebration.

One of our main projects this year will be the Family Survey. FEPEDA has carried out two large surveys before (2000 and 2013). This third survey gives us hopefully a good overview of the current situation in different European countries. The preliminary timetable for launching the survey will be early summer. We encourage families all over Europe to take part in this survey – everybody's response is important!

Our next face-to-face meeting is planned for October (Malmö, Sweden). I do hope that the pandemic is over by then and we can finally meet each other again!

Stay healthy and happy reading!

Sari Paloposki
President of FEPEDA



FEPEDA meetings in 2020

• Bureau:

summer 2020 / skype /
exact date to be confirmed

• Management Committee and General Assembly:

October 2020 / Malmö,
Sweden or skype / exact
dates to be confirmed



Previous FEPEDA Meetings



The first Management Committee meeting this year was held on 4th of April. Due to the COVID19 pandemic the meeting was held virtually by zoom. This was the very first time in the history of FEPEDA to have the Management Committee meeting only virtually. The technics worked well and we had a very active discussion on many issues planned for this year. The Management Committee decided to continue our work with several projects (Photo, Penpal, Youth exchange, Family meeting).

We also had a productive discussion on our Family survey, which we plan to launch in the near future. As for our advocacy work Nicole Schilling from Germany gave an interesting presentation on the World Hearing Forum's General Assembly. Nicole's presentation has been sent by e-mail to all members.

FEPEDA Projects

Photo Campaign "Together for the future"

As part of FEPEDA's 30-year-anniversary we are launching our Photo Campaign. Now it is your great chance to get involved in European activity! Do not miss this, we promise – it is great fun! We are about to start publishing the first photos early summer. If you have any questions, please do not hesitate to contact us.

Idea:

The purpose of the campaign is to aware society in general and public administration in particular, about the capabilities of deaf children and young people, contribute to their empowerment and finally, promote their rights to equal opportunities and non-discrimination.

The campaign is part of FEPEDA's 30-year-anniversary celebration.

What to do:

We kindly ask you to send 10 photos from (different) families of your own organization.

Please send us one photo with a short message like:

- "Hello! My name is Marie and I am 8 years old. I want to be a doctor."
- "Hello! I am John and I am 10 years old. I love rock music. Once I am grown up, I want to be a teacher. "
- The sentences can also be longer, max 8 sentences. (You can for example tell us a little bit more background of your child.)

The photos and messages will be used at FEPEDA's and its members' information channels.

Please send the photos to the Secretariat ([petra.paloposki2\(at\)gmail.com](mailto:petra.paloposki2(at)gmail.com))

Good to know:

For participating in the campaign, please note that you will have to fill in the permission document.

For any further questions you can be in contact with FEPEDA Secretariat:

Petra Paloposki: [petra.paloposki2\(at\)gmail.com](mailto:petra.paloposki2(at)gmail.com)

Advocacy and networking

Please find this FEPEDA's Statement regarding the COVID-19 situation in Europe.

We find it very important to remember the rights of the hearing-impaired children, young people and their families in this current situation.

Please feel free to share this Statement in your own channels.



*Fédération Européenne des Parents d'Enfants Déficients Auditifs
European Federation of Parents of Hearing Impaired Children
Europäischer Verband der Eltern Hörgeschädigter Kinder
Federación Europea de Padres de Niños con Discapacidad Auditiva*

FEPEDA STATEMENT – COVID-19

In the context of this pandemic situation, the European Federation of Parents of Hearing Impaired Children (FEPEDA) is aware that deaf and hard-of-hearing people are facing multiple barriers and calls European, national, regional and local authorities to assure their rights, recognised by UN CRPD:

Right to information: Persons with a hearing disability has the right to access to information simultaneously to the rest of the population. All the information provided online or recorded by audiovisual means (tv broadcasting or through internet) must include subtitling and sign language interpretation.

Right to health:

Access to emergency numbers: Different emergency numbers have been established in this context. It is essential to assure its accessibility through writing and videoconference.

Functioning of hearing aids: It is essential to assure the supply of batteries and spare parts of hearing aids and earring implants, as well repairs services.

Right to education: European children and young people are now studying at home, online education must be accessible for them: speech to text in teacher's instruction and in any other audio material, subtitled audiovisual materials, written indications and guidelines for home work must be used, as well as sign language interpreters for those students who use this language.

Right to (re)habilitation: The public authorities must provide online resources to ensure that early attention and speech therapy services continue for deaf and hard-of-hearing children and teenagers, in order not to affect their progress or make the consequences of their hearing impairment worse, due to lack of specialized attention.

Right to leisure and culture: It is essential that TV programmes, including those for children and young people, are accessible, through subtitling and sign language interpretation.

Right to social protection: A disability in the family is an economical burden. Families with a deaf or hard-of-hearing member must be considered as vulnerable group in the future social protection measures

Right to be consulted: All the adopted measures must be consulted with the organisations representing deaf and hard-of-hearing persons and their families and their sustainability must be assured.

We, deaf and hard-of-hearing children and young people and their parents, will stay at home, but please do not leave anyone behind!

FEPEDA Advocacy and Networking

FCEI-conference

Due to the current COVID19 epidemic FCEI-conference set for this May 27-29 will be postponed until May 26-29, 2021.



World Hearing Day 3.3.2020

On the World Hearing Day 3rd of March FEPEDA launched a press release under the motto chosen by the WHO, Hearing for Life: Don't let hearing limit you.



Fédération Européenne des Parents d'Enfants Déficients Auditifs
European Federation of Parents of Hearing Impaired Children
Europäischer Verband der Eltern Hörgeschädigter Kinder
Federación Europea de Padres de Niños con Discapacidad Auditiva

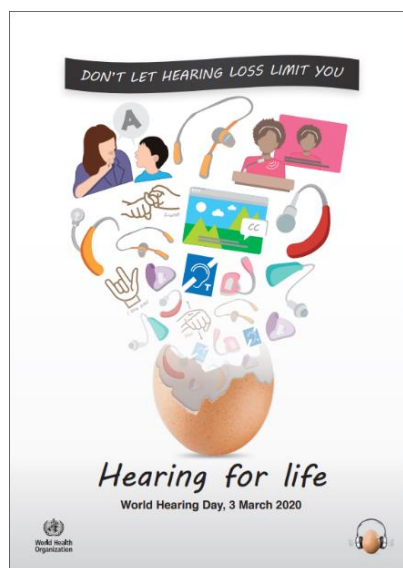
PRESS RELEASE

World Hearing Day 2020 Hearing for life: Don't let hearing loss limit you

(Helsinki, 3.3.2020) The European Federation of Parents of Hearing Impaired Children (FEPEDA), the largest platform representing families of deaf people in the European Union, is endorsing the World Hearing Day campaign, launched by the World Health Organization (WHO).

Under the motto chosen by the WHO, *Hearing for Life: Don't let hearing loss limit you*, FEPEDA wants to remind that thousands of children are born with a hearing loss every year, in the European Union.

The current legislative framework in the European Union and all its Member States enshrines the fundamental rights of deaf and hard-of-hearing people and establishes the responsibility of the public authorities to guarantee their exercise. The EU and its 27 member states have signed the United Nations Convention on the Rights of Persons with Disabilities.



However, early detection of neonatal deafness is far from being a reality in all EU countries. Early intervention is not always adequate, timely and sufficient. Hearing aids (traditional hearing aids and/or hearing implants) are a major financial burden for many European families. Support resources of all kinds are lacking in many schools in Europe. There are not enough aids or support for families. And leisure, culture, recreational activities are often inaccessible to children and young people with deafness.

If we want an inclusive Europe, where no one is left behind, it is essential that EU institutions and national authorities invest in deaf and hard-of-hearing children and young people, ensuring the resources and support they and their families need at the right time, so that hearing loss don't limit them.

President: Sari Paloposki, Secretary General: Cosmin Brasov, Treasurer: Rolf Willm
Address: Teijulantie 18, FI-21420 Lieto, Finland

Tel: +358 50 551 7125, E-mail: sari.paloposki2@gmail.com (president), petra.paloposki2@gmail.com (secretariat)
www.fepeda.eu

Country News

News from Bulgaria

At the beginning of 2020, the Bulgarian Association of Parents of Hearing-Impaired Children launched an online consultation service for the hearing impaired and their families. The platform was developed as part of project BG05M9OP001-2.011-0006 "Equal Opportunities for Hearing-impaired Children and their Families" funded by Operational Program Human Resources Development 2014-2020, Priority Axis 2, „Reducing poverty and promoting social inclusion”, co-financed by the European Union through the European Social Fund.

The main idea was to give an opportunity to people in remote settlements to have access to different types of special services as psychologist, sign language interpreter, supported education and employment, speech therapists

The lockdown of the world caused by the Covid pandemic is hard for everyone, but especially for disadvantaged people. But we faced it continuing to offer all services for people with hearing impairments and their families by the platform.

From the very first day of the state of emergency, all broadcasts news on the national televisions, as well as the daily government briefing, are supported by sign language interpreters in the frontline. This is a big step forward in ensuring equal access to information to the deaf people.

This essential necessity for deaf community is starting to be commented actively on the medias and to focus the attention of whole the society. We are deeply convicted that these times are also times for positive changes. And we will continue to work for it even hard.

News from Czech Republic

Information for 1st FEPEDA newsletter of 2020

Information Centre of Parents and Friends of the Hard-of-Hearing celebrates 30th anniversary

Centre for Children with Hearing Impairment Tamtam is an affiliated organization of our Information Centre and the other successional organization of The Federation of Parents and Friends of the Hearing-Impaired which was founded by parents in 1990. That means that both organizations are celebrating their 30th anniversary this year – same as FEPEDA itself.

In these 30 years we were able to help over 20 000 families with children with hearing impairment in Czech Republic. Everyone who has ever come in contact with any kind of hearing disability knows that since the day one it is a long and stressful journey, especially, with small children.

We are here not only to help them with all the medical matters, but also as a psychological support and just as a friend they can turn to. For this year we prepared all kinds of celebrations. The aim was to get together as many of our current and former clients and to show them how fulfilled can be a life of a child with hearing impairment. We still hope that some of these events will be realized.

One of these events is in October and it is concerned with early intervention – it is a conference called ECI Conference EURLY AID 2020. We do not organize it but we partake and we hope that it will bring some important new info and also that it will draw attention to some current problems.

Our ICPFHH and Tamtam really needed to change the range of work during these challenging times regarding the COVID-19 situation. Counsellors are working from home therefore they use online platforms to connect with the families, they put online a plenty of exercises and other stuff to keep the kids on track and we hope that we will be able to continue our work within previous standards.

Information centre currently participates on all the activities of Tamtam, we are working together and as a team we are trying to handle this situation. One of our greatest projects is creating of the videos in sign language with subtitles. These can be found on one of our websites:

<https://www.idetskysluch.cz/panel-expertu/psycholog/aktualizovano-informacni-servis-pro-neslysici-k-epi-demii-covid-19/>

We see it as very important to provide some informational services to those who cannot hear and might feel insecure in this situation. We hope to overcome this together and soon.

Nikola Hlavicová, editor and specialist ICPFHH

News from Finland



Kuulovammaisten Lasten Vanhempien Liitto ry
Hörselskadade Barns Föräldraförbund rf

Dear All,

The Finnish Association of Parents of Hearing Impaired Children welcomes European families to our family weekend next summer. The camp offers lots of amusement (parkour, fresbee golf, animal shelter, games ect.) for children and a great peer support for the parents. Every year our family weekend gathers together families all over Finland. We are looking forward to organize this camp! Based on current information from public authorities in Finland, there are no plans at this time to cancel the camp due the current COVID-19 situation. Lets hope we can meet up together!

If you got interested, please do not hesitate to contact FEPEDA Secretariat.

Welcome to FAMILY CAMP IN PIISPALA, FINLAND 26.6.-28.6.2020

The Finnish Association of Parents of Hearing Impaired Children welcomes European families to our family weekend. Every year our family weekend gathers together families all over Finland.

Last year we had international guests for the very first time and this tradition we will continue also this summer.

If you got interested, please do not hesitate to contact FEPEDA Secretariat: [petra.paloposkiz\(at\)gmail.com](mailto:petra.paloposkiz(at)gmail.com)

News from France

Situation of employment of deaf and hearing-impaired people in France

This article provides the situation of employment of deaf and hearing-impaired people in France based on figures issued from a survey from INPES (National Institute for Health Prevention and Education) in 2011/2012.

Between 5 and 6 million people are deaf or hearing impaired in France. 1,4 million are of working age:

- One third are unemployed (against 26% for whole population), what means about 500 000 people:
 - o 15% give up working for health reasons (3% for whole population)
 - o 34 % of profound deaf people give up working (1 out of 3)
 - o 15% of hearing-impaired people with average deafness give up working (3 out of 10)
 - o 12% of hearing-impaired people with light deafness give up working (2 out of 10)
- We need to notice that deafness level has an impact of employment rate for deaf or hearing-impaired people. Deeper is deafness, lower is employment rate (34% for profound deaf people and 71% for hearing impaired people)

Opinion on deaf or hearing-impaired people employment

To engage a deaf or hearing-impaired person is rather easy from the point of view of:

- General Public: 58%
- Employees: 48%

- Employers: 42%

Working with a deaf or hearing-impaired person is rather easy for 48% of responding people. This rate can be different according employee situation in work context:

- If several colleagues with disability: 62%
- If only one colleague with disability: 50 %
- If no colleague with disability: 39 %

Support to deaf and hearing-impaired workers

- Sign language interpreters: 62.1 %
- Remote interpretation or phone amplifier: 20%
- Magnetic loop or microphone device: 15%
- Communication interface: 12%

Feeling of deaf and hearing-impaired workers

- 25 % have the feeling to be threaten in their job: they are afraid to lose their job
- 41,8% say that they are disturbed by the noise.

if they have hearing aids and in case of vibrations

- 60% say that their job is nervously tiring, especially for executives
- 50% say that they are in psychological

News from France continued

and 70% among them say that it is due to their job

- 22,1% thought about committing suicide and 45,1% among them say that it is due to their job
- More than 1 worker on 10 say that they attempt suicide and more than 1 out of 5 for professional reasons

Items to work for a better professional inclusion and a better work quality of life

- Deafness would be a reason of non-recruitment and non-access to some jobs
- Lack of information and awareness of people involved in employment on the needs of deaf and hearing-impaired people and ignorance of needed tools to communicate with them would be obstacles to recruitment and professional evolution
- Deafness would hide some skills of deaf workers and their capacities to have jobs with responsibilities
- Deafness would be often associated to less capability
- 74% of deaf workers think they have less opportunities to be promoted than their hearing colleagues
- There is a big strong feeling that efforts are always in the same way, leading to mental and physical tiredness
- Social isolation would be often suffered inside the company

Suggestions to improve insertion and sustainability in employment of deaf and hearing-impaired people

- To reinforce access and accessibility to trainings (initial and continuous) and learning
- To facilitate human aid intervention to make accessible communication (meetings, interviews,): Sign Language interpreters, cued speech coders,
- Inside the company, to provide to deaf and hearing-impaired workers communication and information technologies according their needs
- To reinforce managers awareness and colleagues on deafness and specific communication problematics
- To prevent social isolation and psychological distress of deaf workers inside the company (psychosocial risks)

Written by Jean-Yves HINARD, member of ANPEDA Bureau (treasurer) and member of AGEFIPH Management Committee

ANPEDA: French Federation of Parents of Deaf and Hearing-Impaired children

AGEFIPH: Organisation which facilitates access and sustainability for disabled people to employment in mainstream context.

AGEFIPH informs, advises disabled people and companies and finances expenses to set up a workstation and to arrange a workplace.

News from Spain

FIAPAS PUBLISHES THE RECOMMENDATIONS FOR UPDATING EARLY DETECTION PROGRAMMES OF CHILD DEAFNESS

The Spanish Confederation of Families of Deaf People (FIAPAS), in collaboration with the Commission for the Early Detection of child Deafness (CODEPEH) and with the co-organisation of the Royal Board on Disability, has published a new document as a result of the project 'Updating of early detection programmes for child deafness (Diagnosis, Treatment and Monitoring)', the aim of which is to complete the recommendations regarding neonatal hearing screening programmes.

The new document, entitled 'Updating of Early Detection Programmes for Childhood Deafness: CODEPEH 2019 recommendations (Levels 2, 3 and 4 Diagnosis, Treatment and Follow-up)', which draws on recent scientific evidence, addresses the critical points of update on etiological and audiological diagnosis, as well as issues related to the treatment of congenital deafness, highlighting the importance of binaural hearing and warning that unilateral deafness is not without negative consequences on the child's development, and therefore treatment and follow-up are also required. In this regard, the expansion of indications for cochlear implantation is also addressed.

Programs for early detection of congenital hearing loss have been successfully established mainly in developed countries, after overcoming some conceptual errors against their implantation or some critics of their efficacy. However, some difficulties and weaknesses are still identified in them: the detection of late-onset hearing loss and the percentage of children who did not pass the screening and did not complete the process of diagnosis and treatment, being cases that are lost in the process.

The purpose of this Document is to analyze these problems to determine areas for improvement and to emphasize one of the basic principles for the success of the programs: the continuous training for the interdisciplinary team.

The result of the review process carried out by CODEPEH is drafted as Recommendations for updating the Programs with the evidences of the last decade, the advances in the screening technology, the impact of the present knowledge on congenital infection by cytomegalovirus, the genetic hearing loss researches and control systems of lost to follow-up cases.

The document also focusses on the important role of the families during the whole process, highlighting that Families Associative Movement must be an essential point of support.

