



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



News Letter

1/2019

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Greetings from the President

Dear Friends,

The first issue of FEPEDA's Newsletter is here! Like in the previous Newsletters, you will find in this issue a lot of interesting news from our member countries as well as news from FEPEDA's own activities during the first six months 2019. Please feel free to share our Newsletter with your networks. Your feedback and contributions are also very much appreciated.

Our main priority this year is the upcoming **FAMILY MEETING**, which is right behind the corner! After eight years we are finally gathering European families together again. FEPEDA family meetings have traditionally been full of activities where children and parents can share experiences, learn new things and establish new friendships. Please make sure you won't miss it! I warmly welcome all families to the camp – looking forward to seeing you all in August!

Please also do not forget to register to our Annual General Assembly as it is approaching in October.

Wishing you a happy reading!

*Sari Paloposki
President of FEPEDA*



FEPEDA meetings in 2019

- **Bureau:**
summer/
date to be confirmed/
skype
- **Management
Committee:**
4.-5.10.2019/
Prague, Czech Republic
- **General Assembly:**
5.10.2019/
Prague, Czech Republic





EUROFEST GERMANY

Registration now open

4. – 9. 8. 2019

European Family Camp –

Empowering children and youth
with hearing impairments
and facing future
challenges together

Dorfweil near Frankfurt a.M.



Hintergrundbild: © Taunus Touristik Service e.V.



www.gehoerlosekinder.de



www.fepeda.eu



www.hoergeschaeDIGte-kinder-hessen.de



www.bundesjugend.de

EUROFEST GERMANY - family camp

Dear parents with hearing impaired children in Europe,

Europe takes a week of summer holidays in the Hochaunus Nature Park close to Frankfurt and you can be there!

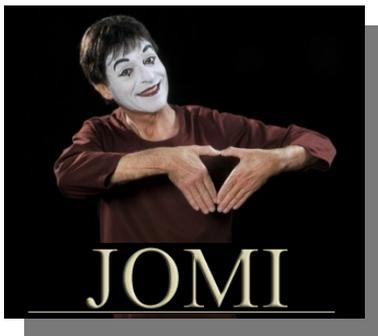
Both German sign language and English interpreters will provide us their translation Service during the European family meeting in Germany. They will translate interesting lectures and reports from different countries as well as exciting workshops. The Topic of EUROFEST GERMANY is:

Empowering children and youth with hearing impairments and facing future challenges together

Lots of news can be expected.

For children and teens with and without hearing impairments there will be great group activities offered. Divided into different age groups and guided by experienced team leaders the programme provides lot of fun, games and workshops all around the great facilities of the holiday resort at Dorfweil. Language barriers are easily overcome in a playful manner and motivation for foreign languages is guaranteed even beyond the one week.

Many organisations and companies are supporting the event, including the Bundeselternverband (=Federal parents association of deaf children), Bundesjugend (= Federal youth organisation) and



FEPEDA, the European Association of parents hearing-impaired children. President Sari Paloposki cordially invites all families to exchange ideas, share experience and to build your personal network in Europe.

New to EUROFEST programme is Star-Pantomime JOMI, who has been deaf from an early age. He is a

well-known and popular artist – his language is understood everywhere. His tours took him to all European countries. With him, pantomime becomes the message. Children and teens can learn more about pantomime with JOMI who will offer two workshops during the EUROFEST.



GUCKMICH.TV also offers an outstanding project for children and teens: They have the opportunity to create jewellery for hearing devices and present the production process in an own Do-It-Yourself video.

This means a great holiday week -for the whole family- is waiting for you.

All further information on EUROFEST GERMANY can be found here:

<https://fepeda.eu/registration-open-for-eurofest-2019>

If you want to ensure your registration immediately you can use the following link directly to the registration form:

Form in English:

<https://goo.gl/forms/C6UXekgibZQbPTpX2>

Form in German:

<https://goo.gl/forms/jIqhRjuheXnIDtZC2>

We are looking forward seeing you at Dorfweil.

EUROFEST project team

FEPEDA Advocacy and Networking

World Hearing Day 3.3.2019

o On the World Hearing Day 3.3.2019 FEPEDA launched a press release which can be found at our website:

<http://fepeda.eu/press-release-world-hearing-day/>

European Accessibility Act

o The European Accessibility Act was finally voted in the plenary session of the European Parliament in Strasbourg on 13th March. The European Accessibility Act is a landmark agreement. However, there is still a lot of work to do. While it will ensure that many products and services will be more accessible for persons with disabilities, it will not make the EU fully accessible. It still excludes many essential areas such as transport, buildings and household appliances. You can read the European Disability Forum's media release:

<http://edf-feph.org/newsroom/news/european-accessibility-act-big-step-forward-long-journey>

Meeting of the European Platform of Deafness, Hard of Hearing and Deafblindness

o The European Platform of Deafness, Hard of Hearing and Deafblindness met in Barcelona on 13th of March.



FCEI 2020

o The 5th International Conference on Family Centred Early Intervention (FCEI) will be held from 27-30 May 2020 in Bad Ischl, Austria.



SAVE THE DATE

5th INTERNATIONAL CONFERENCE
ON FAMILY-CENTRED EARLY INTERVENTION
FOR CHILDREN WHO ARE DEAF OR HARD OF HEARING

Deaf Children, Families and Support:
**Embracing Diversity
for Brighter Futures**

MAY 27th - 30th 2020
Bad Ischl, Austria

www.fcei.at



Country News

News from Czech Republic

News from Information Centre of Parents and Friends of the Hard-of-Hearing (ICPFHH), Czech Republic

The Information Centre of Parents and Friends of the Hard-of-Hearing (ICPFHH) has published a brochure „A Child with Hearing Impairment in Care of Professionals“. At 56 pages, it introduces most important specialists whom the parents of these children meet mostly. What is their role and competence?

How specifically do they help these children to include into the hearing society? What the parents can rely on them? Presented specialists are: a neonatologist, a foniatrist, an early care specialist, team of specialists in implantation centres, an cochlear implant surgeon, a technical specialist setting the CI, a speech therapist and a special pedagogue. They are presented in interviews with them or in author's articles.

Marta Höferová, specialist and editor ICPFHH



News from Finland



Kuulovammaisten Lasten Vanhempien Liitto ry
Hörselskadade Barns Föräldraförbund rf

Welcome to FAMILY CAMP IN PIISPALA, FINLAND 28.6.-30.6.2019

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@gmail.com

Questions?
Want to give feedback?

Please contact
the Secretariat:
petra.paloposkiz@gmail.com



Scan the Qr codes and find
out more about FEPEDA

Replacement of speech processors in Romania – the first steps

Since May 2018, we finally managed to have enacted the legal framework allowing CI recipients to have their speech processors replaced by the National Health Insurance.

The speech processors should be either broken and unserviceable/unrepairable or older than 7 years and not functioning properly anymore.

Even though the number of potential beneficiaries is more than 400, due to budgetary constraints there were allotted funds only for 45 speech processors in 2018 and 100 in 2019(budget proposal).

Our association has closely followed up the process and observed significant differences in each CI clinic's approach in regards to the tender process and selection of the beneficiaries, some clinics taking a proactive stance, contacting and prioritizing the patients with the oldest processors while others have been simply waiting for patients to submit formal requests.

From our perspective is important the fact that these issues were basically teething ones, generated by the novelty character of the legal provisions and uncertainty of the clinics/fear not to make mistakes, rather than hidden agendas or even corruption. Therefore our association is actively cooperating with National Health Insurance and CI clinics in order to ensure proper co-ordination and a common approach amongst the stakeholders and informing the patients on the newly acquired right whilst at the same time asking for a budgetary increase.

I use this opportunity to thank FEPEDA and the national organizations for their support in providing us with up-to-date information on each national CI programme, which was a key element in convincing Romanian National Health Insurance that speech processors should be replaced by the state.

Cosmin-Alexandru Brasov (Hear Life Association - Romania)

News from Spain

FIAPAS, in cooperation with the Spanish ENT Society and Spanish Pediatricians Association, publishes Recommendations to improve the level of detection of children's hearing screening programmes

Early detection programmes for congenital hearing loss have been successfully implemented in different countries, especially in developed countries such as Spain, where Ministry of Health and Autonomous Communities agreed on them in 2003.

With the experience gained since them, the Commission for the Early Detection of Child Deafness (CODEPEH), composed by FIAPAS, Spanish ENT Society and Spanish Pediatricians Association, publishes a document with the purpose of improving the early detection of hearing disabilities in children.

The document, result of a common project carried out by CODEPEH and the Royal Board on Disability (autonomous body depending on the Ministry of Health and Social Welfare), aims to identify and analyse points for improvement the implementation of newborn hearing screening.

Recommendations aim to update the programmes with the evidence appeared in the last decade, addressing to the progress in screening technology, the impact in the programmes of the current knowledge on congenital cytomegalovirus infection and of the genetic studies of hearing loss, as well as the systems for monitoring lost cases in the process and late-onset deafness.

These recommendations also include the need to create a reliable database for case follow-up and the intervention of a coordinated interdisciplinary team focused on the family, as a basis for the success of the programmes.

Finally, it is pointed out that, in the future, hearing screening, genetic study and the study of cytomegalovirus must be integrated into a combined screening. All this with the aim of achieving a complete diagnosis and early treatment of child deafness, both hearing loss present at birth and late and/or progressive onset.

Full document is published (in Spanish) at FIAPAS Virtual Library
<https://bibliotecafiapas.es/publicacion/recomendacionescodepeh2018/>



News from Sweden

The Swedish Association, DHB has its 70th anniversary this year and it was celebrated at the annual meeting. Guests from several other deaf and hearing associations, former board members and many other people from the past years attended the celebration.

We also donated 10 000 SEK through our foundation "Bo Carlssons minnesgåvofond" to sign language pedagogues to their project about developing interactive stories for encouraging deaf children to read more and give them the possibility to "play" with the language.

DHB's 70th anniversary will also be recognized by Lena Fernström, who was long our chairwoman and is currently a chairwoman of one of our districts. She will dive deep into our association's history in the form of articles in our magazine DHB Dialog.



News from Switzerland

PROJECT WAITING ROOM IN SWITZERLAND

Not all parents of hearing impaired children in Switzerland know that SVEHK (Swiss association of parents of hearing impaired children) exists. The association does not get automatically the addresses of concerned families and the families have to do the first step to get in contact with other concerned families.

SVEHK would like to reach all concerned families as soon as possible, preferably at the moment of diagnosis. All professionals of deafness and hard hearing should know that SVEHK exists and recommend concerned parents to get in contact with SVEHK.



To reach this aims, SVEHK

started in the end of 2017 the distribution of his own produced magazine "Bulletin" to ENT-specialists, acousticians, ENT-clinics and logopaedics to 120 addresses in whole Switzerland. In may 2019 starts the personal distribution of a wooden car toy with SVEHK-logo to the same addresses. This toy can be placed at the waiting rooms, where concerned families wait for their consultations.

Committee members of SVEHK will provide the new flyer about SVEHK at the same time and if possible they have a personal conversation with the professionals at the moment of the delivery. SVEHK continues to send the magazine "Bulletin" to the waiting rooms and of course new flyers can be ordered at the SVEHK office at all time. The whole project is financed by sponsoring.

