



News Letter

2/2019

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Greetings from the President

Dear Members,

Year 2019 has been successful and rewarding in many ways. Especially this year the power of volunteers has played a key role in our work. I want to thank warmly all our active members and volunteers for being such a great part of our FEPEDA family and making all the activities possible.

The biggest highlight of this year was our family meeting, which was held in Germany in the beginning of August. After eight years waiting we finally brought families together and gave an opportunity for peer support over the borders. The camp week offered an interesting program both for children and for adults. We spent an unforgettable week together no matter the age, language or country background. I think I am not underestimating that everybody who attended the camp is already waiting for the next one!

In October FEPEDA had its Management Committee meetings and General Assembly in Prague. The General Assembly adopted the next year's action plan, which keeps families, members, cooperation partners and advocacy work in our focus. In 2020 FEPEDA is celebrating its 30th anniversary, which gives the coming year a special importance.

One of our next year's projects is to carry out again a European family survey in order to learn more about the current situation in our member countries. We have also made the decision to start planning the next family camp, which will hopefully be held already in 2021. We are also going to continue our current projects like the Penpal-project, which was launched at the family camp. We will keep you informed of all these by email and through website and Facebook.

On behalf of the Bureau and Secretariat I thank you for your cooperation during this year and wish you all a relaxing and happy holiday season. All the best for the New Year 2020!

Sari Paloposki, President of FEPEDA



FEPEDA meetings in 2020

- **Bureau Meetings:**
spring and autumn /
skype / exact dates to
be confirmed
- **Management
Committee:**
Malmö, Sweden /
3.-4.4.2020
- **General Assembly and
Management Committee
meetings:**
venue to be confirmed /
October 2020 (exact dates
to be confirmed)

EUROFEST GERMANY - family camp

This summer families from all over Europe were invited to FEPEDA's latest family camp: EUROFEST GERMANY in Dorfweil near Frankfurt. Families spent one exciting and inspiring week with lot's of experts and great entertainment.

Honorary Chairman Lothar Wachter and patron Mark Weinmeis-ter, Hessian Deputy Secretary for Europe, personally opened the official congress. Both expressed the importance of international exchange to further improve participation in leisure activities as well as in education and profession.

In the course of the conference, high-ranking experts and representatives of European associations discussed the question how young people can make themselves "fit for future challenges together through empowerment". The parents particularly appreciated the comprehensive information offered by psychologist Dr. Oliver Rien, who was able to give the parents many tips and tricks for everyday life with hearing-impaired children as well as interesting background information. Sari Paloposki, Finnish President of FEPEDA, presented the almost 30 years of association activities and focused on offers for families in Europe. For the first time, Christoph Mies from the school initiative "save use of internet" (Sicher im Netz) presented recommendations how to introduce the world-wide-web and smarhtone applications safely to children to an international audience. Petra Blochius, Managing Director of the Frankfurt Foundation, presented the newly established EUTB - unabhängige Teilhabe Beratung (EUTB - Independent Participation Consulting) in addition to the Foundation and deepened the topic of empowerment in a workshop. The following exchange of experiences with successful offers and concepts made in Finland, Spain and Romania were very interesting, so that the participating families received many great ideas and suggestions for their home countries and regions.

For the children and young people from Germany and Europe, the Bundesjugend, association of young people with hearing disabilities, had put together an impressive children and youth programme run by great team leaders. Divided into age-groups, the children were able to explore the great outdoor facilities by a paperchase rallye, geo-caching tour, minigolf tournament, beach volleyball or just relaxing on the play ground. They also created a wonderful YouTube video with the professional company and internet movie provider GuckmichTV. How to pimp up your hearing aids can now seen not only all

over Europe. A further outstanding opportunity were the pantomime workshops with star pantomime JOMI. They experienced quite successful how strong communication can be by just using gesture and facial expression as well as body language. They went directly on stage with their very first performance and allowed a fun evening for all families.

Before the family camp closed with a cultural festival where culinary specialities and typical country nationalities were exchanged, all families visited the European Central Bank in Frankfurt. They were given a guided tour about tasks and functions associated with the euro and the european politics.

Families and especially children gained international contacts and became friends with other equally affected children and young people from Europe for the first time. The new contacts and valuable experiences strenghtend all far beyond the family camp. Now everyone can't await registering for the next family camp, of course.



text: Nicole Schilling

Previous FEPEDA Meetings

FEPEDA's General Assembly and two Management Committee meetings were held in Prague, Czech Republic on 4th – 5th October, 2019. The meetings took place at the premises of our Czech member association and we also had the possibility to learn more about their activities. A big thank you to Marta Höferová and her colleagues for hosting us during the whole weekend!

The General Assembly approved last year's accounts and activity report as well as next year's budget and action plan. Discussions were productive and fruitful. All in all next year will be full of activities and each member's active participation is highly appreciated!

The General Assembly also accepted a new Associate member – AURES Foundation from Georgia. We warmly welcome them as part of FEPEDA family!



Advocacy and Networking

European Disability Forum (EDF)

FEPEDA participated, as full member, in European Disability Forum (EDF) Annual General Assembly (AGA), which was held in Brussels on 1st and 2nd June 2019. FEPEDA was represented at the meeting by André CUENCA, Vice-President of FEPEDA.

FEPEDA also nominated André CUENCA as NGO (Non-Governmental Organisation) candidate for EDF Board. AGA was preceded by the conference "Smart travel: Partnership and technology making European travel more accessible" and followed by a workshop on how to engage with the UN Committee on Elimination of Discrimination Against Women to promote the rights of women and girls with disabilities, attended by around 50 people.

General Assembly, Election of board members

The General Assembly elected two new board members:

National Councils: Luisa Paola Bosisio representing Italian Disability Forum

NGO: Francisco Vano Ferre from International Federation of Persons with Physical Disability

The General Assembly included a workshop on the European Semester, with a keynote speech by Katerina Ivankovic-Knezovic, the Director responsible for social affairs in the European Commission's Directorate General for Employment and Social Affairs. She spoke about the Commission's commitment to the EU Pillar of Social Rights and presented some of the key advances to emerge from the European Disability Strategy.

European Elections

The General Assembly also discussed the results of the European Elections campaigns several members led at European and national level. EDF unanimously adopted a resolution calling for the re-establishment of the Disability Intergroup.



FEPEDA Advocacy and Networking

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

The European Platform of Deafness, Hard of Hearing and Deafblindness met in Brussels on 30th October, 2019. As special guest of the meeting Mher Hakobyan from European Disability Forum (EDF) gave a presentation on the latest news and activities of EDF.

FCEI 2020

The 5th International Conference on Family Centred Early Intervention (FCEI) will be held on 27-30 May 2020 in Bad Ischl, Austria. The registration is now open - don't miss the the early bird -fee!

The conference gathers together professionals and parents all over the world and offers a great opportunity for networking.

One of the keyspeakers at the conference is FEPEDA's President Sari Paloposki giving a presentation on family support throughout Europe.

Further information on the conference is available at:

<http://www.fcei.at>



FEPEDA Advocacy and Networking

World Hearing Forum

The World Health Organization (WHO) works in the field of hearing with the aim to prevent hearing loss that occurs due to causes such as ear infections and noise; and to ensure access to diagnostic, therapeutic, rehabilitative and supportive interventions for all those who have hearing loss.

In 2017, the World Health Assembly with participation of all countries adopted a resolution on prevention of deafness and hearing loss. This resolution calls upon all countries and partners to take concrete steps to address hearing loss. WHO has launched the World Hearing Forum as a global advocacy alliance to promote action for hearing through multi-stakeholder engagement.

Nicole Schilling represented FEPEDA at the first meeting of this Forum held at WHO headquarters in Geneva, bringing together nearly 200 partners from across the world.



Conference in Lithuania

FEPEDA's Lithuanian member association PAGAVA celebrated its 25th anniversary and arranged a conference "Power of collaboration in support for deaf children and their families". On behalf of FEPEDA Sari Paloposki gave a presentation on collaboration at European level. The conference gathered together a large group of Lithuanian families and professionals in this field. FEPEDA congratulates PAGAVA for its great work during the past years!



Country News/ /News from Bulgaria

In the period 9-18 September, the Association of Parents of Hearing-impaired Children hosted an international youth exchange "The Beauty of the difference", implemented with the financial support of the Erasmus + program. Hearing impaired young people from Poland, Romania, Lithuania, Serbia, Bosnia and Herzegovina, Albania and Bulgaria spent an unforgettable ten days in the enchantingly beautiful seaside village Sinemorets to discuss topics including human rights, prevention of social exclusion, social dialogue, such as the basis of the values of European self-awareness. Workshops, games and presentations were mixed with tours of ancient sites around the area - Ahtopol, Tsarevo, Sozopol. In the mysterious Strandja we set off by boat on the Veleka River. During the exchange, we commented on the implementation of European and local disability policies in the partner countries of the project, shared good practices, discussed the role and importance of education, enhancing competencies, the role of advocacy and empowering young people with hearing impairments. We also met with the representatives of the local authorities and took part in the largest cleaning action "Let's clean Bulgaria". We did not miss presenting Bulgaria in the national evening with folk costumes, and our guests made their first steps in the Bulgarian dances. Our partners had also prepared many interesting and delicious presentations :) Thank you all for your dedication and unforgettable moments! We will miss you!



News from Czech Republic

Information Centre of Parents and Friends of the Hard-of-Hearing has published, in a specialized magazine The Children's Hearing, volume 3/2019, **a deep interview and questionnaire on situation of care for children with hearing impairment in different European countries.** Namely, the readers can compare systems in Finland (interview with Sari Paloposki), Bulgaria, Romania and Switzerland (questionnaires with Antoaneta Yarichkova, Cosmin Brasov and Dominique Boomsma). Many thanks to them for time and effort which they put into it!

More about the magazine and the activities of Czech association you can get at their just **launched new website!** English version provides also information on FEPEDA and most important news, especially at international level:

<https://www.infocentrum-sluch.cz/en/>



News from Finland

Information booklet for the parents

The Finnish Association of Parents of Deaf and Hard of Hearing Children (The KLV L) has published an information booklet for parents.

The booklet is designed to meet the needs of parents to get information. It consists information on different types of hearing loss and provides answers to questions parents may have after having received the first information after the diagnosis. It also includes tips and information on hobbies, day care and school system.

You can find the booklet our website. For the moment, the booklet is available only in Finnish:



https://www.esitteemme.fi/kuulovammaisten_lasten_vanhempien_liitto/MailView

Join the Summer Camp in Finland on 26.-28.6.2020!

The Finnish Association of Parents of Deaf and Hard of Hearing Children organizes each summer a Summer Camp. Next summer the camp will be held in the end of June. Come and join us to have the best summer weekend ever! We can guarantee adventure, good company and the best atmosphere! There will be organized program for the whole family.

If you are interested in joining our camp, please contact FEPEDA Secretariat (petra.paloposki2(at)gmail.com). More information on the camp venue can be found:

<https://www.kannonkoski.fi/kannonkoski-in-english>

News from Romania

Between 18-24 August 2019, our association organized another edition of our summer camp for hearing impaired children and their families in the scenic landscape of Bucovina, in northern Romania. For the first time we had guests from abroad, the representatives of the Polish Association of children with hearing impairments "I WANT TO HEAR", which gave us the opportunity to share our experiences and try to implement the lessons learnt from each other's country.

Whilst starting from May 2018, Romanian National Health Insurance has been covering the replacement of broken or older than 7 yrs speech processors, the first year was a learning one for both clinics and patients, with the procedures and funding far from being perfect.

Through hard work, raise-awareness campaigns and involvement of all the interested parties, 2019 marked a definite improvement with the three-fold increased budget and all CI clinics implementing the programme. We've already identified the next objectives which are to further increase the budget in order to cover all the needs, to include BAHA speech processors in the programme whilst at the same time to make sure that the new patients will benefit from bilateral CI implantation without any delays.

This summer we finalized the project Joy of Sounds, through which we established two early intervention centers together with the schools from the deaf from Iasi and Vicovu de Sus and we created the first free online library with rehabilitation materials translated and adapted for Romanian language, with support from Orange Foundation.





Studying by oneself, going alone to hospitals and doctors, enjoying a theatre performance in equal conditions to the rest of the citizens are not always possible for people with a hearing disability using hearing aids, due to the lack of hearing accessibility.

Under the motto A sense of living, FIAPAS aims to create awareness about that, promoting access and use to hearing devices, as induction loop, which in connection to the hearing aids (traditional hearing aids and/or implants) make accessibility possible.

Last month of September, FIAPAS launched its yearly campaign, which may be visited, using the signal T related to the necessary telecoil:

<http://www.queloescuchetodoelmundo.com>

During this public event, FIAPAS also launched its Manifiesto on the international day of deaf people, where it is highlighted that in Spain, over 97% of people with deafness and their families, who have chosen oral language as their vehicular language of communication by using hearing aids and implants, demand an accessible environment allowing them to take part in the whole stock of historical, political, cultural, legal and other facets of the society they live in and share, and to which they contribute like everyone else.

https://www.youtube.com/watch?v=55Sd-RAol_o

News from Switzerland

Swiss Parents Conference

It is the highlight of the year: During autumn, the members of the Swiss Federation of Parents of Hearing Impaired Children (SVEHK) meet for a weekend with a varied program for adults and children. This year, the Parents Conference took place in Ticino on the 19th and 20th of October. Almost 300 participants from all over Switzerland travelled to the conference – families, professionals and young adults who would be in charge of taking care of the children.

Thanks to the rainy weather the participants got to know each other even more closely. Whilst the children started out being welcomed by the childcare staff, the adults attended an introductory presentation with the following topic: Going through life with self-confidence despite a hearing impairment.

As is customary every year, the workshops came in a wide array of topics. For example, parents could exchange their experiences during the time after the diagnosis. Other important topics were «the acceptance of being different» and «questions about the identity and adolescence of the hearing impaired». During the workshop «Friends, spare time, love» parents had the opportunity to hear about the life of young adults affected by hearing impairment and were able to ask them questions. For other parents, «laughter yoga» and «relaxation» were on the agenda.

The marketplace offered parents a wealth of information with representatives of schools, of institutions and equipment providers present.

The board thanked Monika Schlachter-Plüss warmly for her work, since our managing director will retire next spring.



It was her 18th and unfortunately last Parents Conference. The thunderous applause showed the appreciation from all those present for her dedicated work.

This weekend passed by quickly and even the constant rain could not diminish the good spirits. Agi Gasser, President of the Swiss Federation of Parents of Hearing Impaired Children, concluded by thanking all the helpers for this successful Parents Conference and is looking forward to seeing everyone again at the next Swiss Parents Conference in 2020.



Scan the QR codes and find out more about FEPEDA

Questions?
Want to give feedback?

Please contact
the Secretariat:
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Happy Holidays!