



News Letter

1/2018

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Greetings from the President

Dear Members,

The first six months this year have been busy, but rewarding. I would like to once more thank the former President Sonia Zamora and FIA-PAS for their great efforts in leading FEPEDA during the past three years. I will do my very best in serving you for the next three years.

At our three meetings this year we have had productive discussions and made progress in many ways. We have analyzed our strengths, weaknesses, opportunities and threats (SWOT) which has given us a lot of good information and tools for our future work. One of our priorities this year is to increase awareness of FEPEDA at family level. This includes sharing of information, networking, encouraging member countries to invite foreign families to their family events – just a few examples to mention. The planning of the FEPEDA Family Camp 2019 has also started and will be worked further by our Family camp working group. Please follow up closely our website and Facebook for further information!

At advocacy level our cooperation with other organizations has been active including the Microsoft conference in February, the European Disability Forum's General Assembly in May, meeting with GPODHH and FCEI-conference in June. On the World Hearing Day 3rd of March we launched a press release on equal rights on hearing aids. I hope it has been useful in your work at national level.

I would like to take this opportunity and welcome you all to Bukarest, Romania, where the next Management Committee meetings and General Assembly will be held on 5th – 6th October, 2018.

Looking forward to seeing you all there!

Enjoy the summer!
Sari Paloposki
President of FEPEDA



Country News

News from Switzerland–

Invitation for the annual family camp

Switzerland is pleased to invite families from members of FEPEDA to their annual family camp.

This year's camp takes place in Leysin, canton Vaud, the French part of Switzerland on 27th and 28th October 2018.

The program starts on Saturday at 13.00 and ends on Sunday after lunch approx. 14.00. The workshops are simultaneously translated in German, French and Italian; and of course in sign language. There will be also a separate children's program in place.

Price for a couple is CHF 270.00 ; for a single person CHF 180.00.

Children are free.

These prices include accommodation, dinner on Saturday evening, breakfast and lunch on Sunday.

We will be able to send more information after release of the program.

text SVEHK

"Asculta Viata!" - Hear Life!



text Cosmin Brasov, pictures Iulian Dumitru

News from Romania–

Romanian Association of hearing impaired persons „Hear Life!“ was established in 2007 at the initiative of the parents of hearing impaired children at a time when information about cochlear implant and the rehabilitation process was scarce and the national CI programme had been blocked for roughly two years.

11 years later, we comprise of more than 250 families from throughout Romania and have managed to organize regular family events (summer & winter camps), workshops and seminars for professionals and parents while also having a magazine, website and Facebook page (Asociatia "Asculta Viata!" - Hear Life!). In the last year we managed to create two early intervention centers in partnerships with schools for the deaf from Iasi and Vicovu de Sus as well as a pottery workshop at the school for the deaf in Iasi, all through private-funded grants.



In regards to the national legislation, we have implemented various lobbying and advocacy campaigns targeted at improving the relevant legal provisions, disseminate information about the legal rights and provide legal advice to the parents of hearing impaired children. Information received from similar associations from abroad including FEPEDA members, concerning their national CI programme, proved invaluable, as we finally managed to convince the Ministry of Health and the National Health Insurance on the importance and benefits for having the sound processors replaced within the National CI programme. We hope that the bill modifying the legal framework will enter into force in the first half of 2018. As the bill entered in force in May, we are keeping its implementation under scrutiny and looking to further adjust the budget according to patients' needs.



Scan the Qr codes and find out more about FEPEDA



Meet the new Bureau –

The new Bureau was elected in October 2017 for the next three years:

- Cosmin Brasov, Secretary General, Romania
- Carmen de Lamo, Vice president, Spain
- Sari Paloposki, President, Finland
- Darina Pantaleeva, Vice president, Bulgaria
- Rolf Willm, Treasurer, Germany
- André Cuencá, Vice president, France

News from Germany – Networking in Hessen

Thanks to a lot of volunteer work, we founded an open network in Hessen for all associations, self-help-groups and initiatives that are interested in improving educational standards for hearing impaired pupils. Legislation and theoretical support looks okay, but access is not guaranteed hessian-wide. Why not?

We came together at a round table and agreed on 10 most important points that need to be improved urgently. We forwarded the memorandum including all 10 points to the responsible authorities. That was 3 years ago. Since 2015 we have the opportunity to take part in a working group focusing on the education of hearing impaired children at special as well as regular schools. Hopefully by end of this year we will reach a milestone.

FERIENTREFFS at special schools for regular pupils

“What’s the next FERIENTREFF about, mum? I can’t wait for it!” Nicole Schilling usually gets that question 4 times a year from her daughter about several weeks before school holidays start.

“FERIENTREFF” means the get-together of families with hearing impaired pupils who go to regular schools. These meetings usually take place at Johannes-Vatter-Schule in Friedberg, which is a special school for pupils who are hard of hearing or deaf.

Each school holiday, the families are welcomed to enjoy the great facilities there. The affected children as well as their brothers and sisters are invited to take part in cool leisure activities: creative, communicative, and sportive. They have parents, teachers or team leaders who offer geo caching, pottery, painting, carving pumpkins, sport in the gym, carpenters and so on.

While the children are enjoying themselves, the parents come together not only for a cup of coffee but also for exchanging experiences and sharing difficulties their children face every day. “We help to keep ourselves up to date in terms of technical, educational and social aspects,” informs Nicole, vice-chairwoman of German association “Elternvereinigung hoergeschaedigter Kinder” in Hessen.

“Why are we organising this in the 6th year now? - If not, we would lack of contacts among equals and our children would miss chances,” explains Nicole. Often the hearing impaired pupils at regular schools are the only ones among 1000 pupils. “By just ‘seeing’ other children with hearing aids we offer a piece of empowerment. The better they know each other, the better they encourage themselves.”

News from Bulgaria – The Beauty of Difference

Implementation period - September 2018

The theme of the project “The Beauty of Difference” is to create an opportunity for self-expression and exploration of a new culture, as well as to stimulate the development, social inclusion and active participation of young people with hearing disabilities in society. The project is an international exchange involving 32 young people, 8 from Bulgaria, Lithuania, Poland and Romania with hearing impairment. The exchange is ten days long and will take place at the end of September 2018 in Tsarevo Municipality, the southern Black Sea coast. Among the main topics that young people from the four countries will discuss are European and local policies for people with disabilities, good practices, the role and importance of education and empowerment, advocacy and its role



text and pictures Nicole Schilling

Questions? Want to give feedback?

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



Equal chances for children and young people with hearing impairment and their families

Implementation period 04 / 2018 - 12 / 2020

Through this project, ARDUS offers an innovative model for improving the quality of life of people with disabilities by establishing an active mechanism for cooperation with stakeholders who are involved in the professional realization of people with hearing impairment.

The main objective of the project is to create prerequisites for active social inclusion of children and young people with hearing impairment and their families as one of the most vulnerable groups in our society. Thus, the proposed activities are aimed at raising the awareness of the public about the problems and opportunities of people with disabilities and changing the public attitudes towards them.

The main focus is the improvement of knowledge and skills, as well as the enhancement of the personal and social competences of hearing impaired people and their families, as well as effective partnership and dialogue with the administration, the social partners and society.

text ARDUS

News from Czech Republic –

Information Centre of Parents and Friends of the Hard of Hearing, Prague, Czech Republic

In the first half of 2018, we have published two other issues of our specialized magazine The Child's Hear on the topic Relationships in a Family (with a hearing impaired child) and Care for a Child with Multiple Diseases. Thanks to new PR specialist, we have new financial partners to contribute our work.

There was the 22nd Garden Party which takes place once a year in June. There are cultural shows as well as plenty of activities for children, everything interpreted into Czech Sign Language (CSL) and introduced by a Czech famous actor Jaroslav Dusek.

This was released also in Czech TV.

Visit from min 2:11:

<http://www.ceskatelevize.cz/ivysilani/10265744641-zpravicky/218411000160612>

We also joint a large event Night of Museums with a specialized program for hearing impaired people. 56 of them enjoyed a guided and into CZL translated tour in 6 museums in Prague.

text Information Centre for Parents and Friends of the Hard Hearing

News from Lithuania –

Workshop for young families with deaf and hard of hearing children

On April 21-22, PAGAVA organized a two days' workshop for young families with deaf and hard of hearing children. The topics of the event included prevention of alcohol consumption, how to talk with children and teenagers about alcohol, and ways to avoid addictions.

The aim of the event was to strengthen family health by involvement into active leisure activities. It turned out, that health topics are very important for young families as there were more those who wished to participate in the workshop than were expected. Therefore, a similar workshop will be organized in autumn.

While parents were learning "to live healthy", their children were involved in a separate education program organized by PAGAVA staff and volunteers. Sign language interpreters participated in all activities ensuring access to information for all participants.

Organization experience shows that during workshops and seminars parents not only receive useful information but can also meet other families with hearing impaired children; they can discuss common problems and share ways of solving them alongside with consultations with specialists.



Scan the QR codes and find out more about FEPEDA





Charitable concert Our Earth is Alive

On April 6, PAGAVA for the fourth time organized a charitable concert Our Earth is Alive dedicated to commemorating World Earth Day. The concert was held at Vilnius Evangelical Lutheran Church. The programme featured organist Jūratė Landsbergytė, singer Asta Pilykaitė with her children students, Victoria Maria Zabrodaitė, Teachers Song Theater from Gabija Gymnasium, and poetry read by Gitana Merkelienė, Klaudia Merkelis, Edmundas Atkočiūnas. Sign language interpretation was provided.

The performers donated their music and poetry to children with hearing impairment. The funds raised during the concert will be used to purchase hearing aids to hard of hearing children.



text and pictures PAGAVA

Training session for deaf and hard of hearing young people

On May 12-13, a training session for deaf and hard of hearing young people was organized in a beautiful country side place. It was aimed at promotion of healthy life and prevention of harmful habits in young people. Lectures and outdoor activities were organized.

The youth were introduced and practically taught how actively spend their leisure time. Visiting lecturers introduced participants not only to the risks of harmful habits but also to the principles of responsible family planning in order to avoid unplanned pregnancies and alcohol-related disorders in babies, which is becoming an increasingly common problem in a society facing difficulties in the family. There were also discussions about how to avoid addictions, why alcohol ads are being developed and other issues challenging young people.

All activities were aimed to develop and strengthen the motivation of young people not to use alcohol/drugs/ tobacco. The trainings contributed to the education of young hearing impaired people, as specifics of their disability limits accessibility to written information in press or internet, where terms used are not always clear to them. During trainings, sign language translators participated in all activities.



FEPEDA meetings and events

Let's bring FEPEDA teens together

When we met in Madrid for the GA last year the idea was born, to bring our teens together during FEPE-DA conventions. In Frankfurt we organised it the first time during the MC meeting in April 2018. The excitement of the teens was really high because it was also the very first time taking part in an international youth group. Team leader Lena Dworschak and girls from Finland, Romania and Germany got to know each other easily; they took pictures of Frankfurt's skyline, sights and funny group pictures. Soon after they printed the photos and created their own individual photo album. They also visited a brand new museum and enjoyed doing handcrafts there. Everybody was very happy and took much more home than only the unique album.

text and pictures Nicole Schilling



Upcoming FEPEDA meetings and events

Management Committee meetings and General Assembly,
5th to 7th October 2018 in Bukarest Romania.

Family camp in Germany 2019 – further information follows soon!

FEPEDA Advocacy and Networking



text and pictures Petra Paloposki

FCEI-congress in Bad Ischl

The 4th FCEI-congress was held in Bad Ischl (Austria) on 13th-15th of June. The main theme of the congress was "Principles into Practice". The congress gathered together researchers, professionals and parents from 36 countries all over the world.

Pre-conference 13.6.

Before the main conference a pre-conference was held offering especially parents a great opportunity to meet each other and tell about their families and situation in their own countries. There was also a panel discussion, which was facilitated by Janet DesGeorges (USA) and Sari Paloposki (Finland). The theme of the panel discussion was "Parent Leadership" and parents on the panel from Austria, India, New Zealand, Romania and South Africa shared their experiences and gave useful tips to other parents.

Main conference 14.-15.6.

The main conference was officially opened with greetings from children all over the world. Via these video greetings children shared who they are and what they want to be when they are grown up.

The main conference included many interesting presentations including latest news of genetics, technology, role of the fathers, social-emotional development of hearing impaired children - only few examples to mention. Also parents' perspective was well represented by Anisa Ibrahimovic from Bosnia-Herzegovina ("Glocalization") and Joel Tonny Mwesigwa from Uganda ("Understanding fathers")

Most of the presentations are available at the official website of the congress on www.fcei.at.

The 5th FCEI-congress will be held on 27th – 30th May, 2020.



FEPEDA Advocacy and Networking

Press release on equal rights to hearing aids published on 3rd March 2018

<http://fepeda.eu/the-world-hearing-day/#more-1849>

Joint statement on equal rights in emergency situations (emergency calls)

<http://fepeda.eu/emergency-call-to-the-council/#more-1892>



EDF, General Assembly was held in Vilnius in May 2018

<http://www.edf-feph.org/newsroom/news/europe-all-its-people-we-gathered-lithuania-demand-decent-standard-living-all-persons>



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