



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

2/2018

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Greetings from the President

Dear Members,

When writing this the year 2019 is just around the corner. This year has been productive for FEPEDA in many ways. We have focused our efforts at member and family level, not forgetting our work at advocacy level. We have strengthened our work with our cooperation partners not only in Europe, but also globally. I am sure that in each of your home countries the year has been full of activities as well – in this second newsletter of the year you can read many interesting news from our member countries.

In October we had our Management Committee meetings and General Assembly in Bucharest, Romania. We had good discussions on many important topics. The action plan for the next year was adopted. In the coming year 2019 our main priority will be the FEPEDA Family Meeting “Eurofest Germany”, which will be held in the beautiful surroundings in Dorfweil, Germany in the beginning of August. I hope that you will actively spread Save the date –poster in your home countries. FEPEDA has organized family meetings since the beginning of its history. Family meetings have always been very popular offering European families a great opportunity to learn from each other and establish new, lifelong friendships. The main theme of the next family meeting is “Empowering children and youth with hearing impairments and facing future challenges together “ - the program of the week will be built around this theme. I warmly welcome all families to our family meeting!

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 2019!

Sari Paloposki
President of FEPEDA

Questions? Want to give feedback?

Please contact
the Secretariat:
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FEPEDA Family Meeting – Eurofest Germany



EUROFEST GERMANY

Save the date
4. – 9. 8. 2019
European Family Camp –
Empowering children and youth
with hearing impairments
and facing future
challenges together

Dorfweil near Frankfurt a.M.
Further information will be available soon.
Please refer to
www.hoergeschaedigte-kinder-hessen.de

Scan the QR codes and find out more about FEPEDA



text and pictures Nicole Schilling



EUROFEST GERMANY 4.-9.8.2019

FEPEDA's next European family camp is scheduled for August 2019 in Dorfweil near Frankfurt am Main. The main topic for parents, children and teens from all our FEPEDA member associations will be "Empowering children and youth with hearing impairments and facing future challenges together". Today we like to share some more information about the beautiful location for the family camp. The small village Dorfweil is part of Schmitten and can be found 45 km north-west of Frankfurt am Main.

Please enjoy a look into the brochure of the holiday resort:

"Our Christian holiday complex is located in the Hochtanus nature park in the panoramic area of Dorfweil, a small village in the Taunus hills, part of Schmitten, a climatic health resort. The beautiful location, in grounds of over 7.5 acres, is set in a wooded area and the favourable climate, together with a friendly atmosphere, offers an ideal setting for relaxation, recreation and reflection." ...

"Whether you explore the 2,000 year old cultural landscape around the holiday resort or enjoy a community game, we offer diverse recreational activities which make a child's heart beat faster! Does your child like to try some archery or listen to stories around the crackling camp fire? Or run barefoot across the field and play outside, possibly discovering the rope-climbing garden?"

http://wordpress.p421316.webspaceconfig.de/wp-content/uploads/2017/10/160901_Image_FSD_EN.pdf

The holiday resort at Dorfweil offers a great number of activities in-door as well as outdoors. Don't forget to mention that there is also a sauna and a nice swimming hall.

Of course, you will be offered an interesting programme for the whole family. You can look forward an official congress day to learn more about empowering children and teens with hearing impairments and there will be a fun programme for kids and teens, too.

Further information will be available beginning of 2019. Registration documents are planned to be ready by end of January 2019.

FEPEDA Advocacy and Networking

The European Platform of Deafness, Hard of Hearing and Deafblindness had a meeting in Brussels in the beginning of October. At the meeting we especially discussed the European Elections 2019 and the importance of making them accessible for deaf, hard of hearing and deafblind people.

The Platform has also published the new flyer, you will find it:
<https://www.epdhdb.eu/wp-content/uploads/2018/11/Flyer-Plataforma-PRINT.pdf>



FEPEDA MEETINGS IN 2019

Bureau:
8.2.2019 at 6 pm Finnish
time / skype
summer / date to be
confirmed / skype

Management Committee:
12. – 13.4.2019 / venue to
be confirmed
4. – 5.10.2019 / Prague,
Czech Republic

General Assembly:
5.10.2019 / Prague, Czech
Republic

FEPEDA Meetings GA+MC in Bucharest 2018



Country News

Country News - Bosnia and Herzegovina

Association for support to children with hearing and speech disabilities "Eho" (Echo) is an association of parents, which primary aim is to achieve necessary psychological, social, diagnostic, rehabilitation and education assistance to help children with hearing / speech disabilities in Canton Sarajevo and Bosnia and Herzegovina. Additionally, Echo is the only association in Bosnia and Herzegovina whose activities recognize and meet needs of cochlear implant users.

The Association is registered 2005 in Canton Sarajevo (which is the largest canton in Federation of Bosnia and Herzegovina). In the past few years the Association's activities were intensified resulting in different implemented projects.

Specific objectives of Association's activities are:

- further professionalization of the Association,
- creating local policies, especially in terms of early intervention, education of children and young with hearing / speech disabilities, strengthening volunteering and partnership with governmental organisations, international cooperation etc.
- membership in relevant international nongovernmental organizations, and presence in local and international events, conferences and meetings.

Association is not financed by the government and our activities are financed and provided through grants and donations, or even by families themselves. Therefore, we have limited resources to effect significant changes.

But, by efforts of Association's members, Eho gained its visibility both at regional level and wider by taking actions to:

- improving legal framework in order to ensure more rights for children with hearing / speech disabilities (several lobbying and advocacy campaign resulted by adopted by-law which partially improved cantonal legislation relevant for this population),
- initiating and supporting development of cost effective programmes and projects for the early intervention services which are not provided by the government (including newborn hearing screening, which concept is developed and presented to the federal authorities),
- ensuring the minimum necessary conditions in educational institutions, necessary hearing, technical and surdo-technical devices (members are provided by speech processors, hearing aids, spare parts, FM systems etc.),
- establishing parent to parent support (through social media, parental forums, family events etc.),
- better exchange of information and experiences, especially in area of legal rights and legal provisions, informed choice and decision making, also family social and emotional support,
- greater social inclusion and independence of children and young deaf and hard of hearing persons,
- improvement of rehabilitation, that is on a very unsatisfying level,
- promoting "Spend to Save" campaign
- establishing cooperation with the Federal Institute for Public Health in implementation of the WHO Resolution on the prevention of deafness and hearing impairment,
- initiating introduction of inclusive standards for deaf people in health care and access to health services,
- initiating implementation of the European Accessibility Act in the Federation of Bosnia and Herzegovina in the part related to the deaf and hard of hearing people,
- initiating campaign to raise awareness of the consequences of deafness and its prevention in children and youth.

Our long-term plans are to:

- develop successful programme/services for deaf and hard of hearing persons and to gradually introduce them into the public systems, or,
- force that successful programme / services became financed by the state although they are provided by the private sector.

We believe that membership in FEPEDA will significantly contribute to the fulfillment of specific objectives and further activities of the Association by sharing experience and using best practice of all members.





Country News - Bulgaria

On September 2018, the Association of Parents of Hearing Impaired Children hosted an international youth exchange "The Beauty of Difference", with the financial support of Erasmus +. Young people with hearing impairment from Poland, Romania, Lithuania, and Bulgaria spent an unforgettable ten days in the pretty village of Sinemorets to discuss topics including human rights, prevention of social exclusion, social dialogue, as a basis for the values of European self-awareness.

Workshops, games and presentations were mixed with a tour of ancient sites around the area - Ahtopol, Tsarevo, Sozopol. And in the mystic Strandja mountain we rode in boats along the Veleka River.

During the exchange, we had a long discussion about the implementation of European and local disability policies in the countries which were part of the project, shared good practices, discussed the role and importance of education, the role of advocacy and the empowerment of young people with hearing impairment.

We also met the representatives of the local government and took part in the largest cleaning action "Let's clean Bulgaria". Also, we did not forget to present Bulgaria in the national evening with folk costumes, and our guests made their first steps in the Bulgarian horo (traditional dance). Our partners also prepared very interesting and tasty dishes :)

We thank everyone for their dedication, sharing and unforgettable moments! We already miss you!



Country News - Czech Republic

News from Information Centre of Parents and Friends of the Hard-of-Hearing (ICPFHH), Czech Republic to FEPEDA Newsletter (to be issued in December 2018)

(Sent on 3rd of Dec by Marta Höferová, specialist and editor ICPFHH)

On September, 26th, our closely cooperating organization Center for Children with Hearing Impairment Tamtam, issued a new application Medvěd – znakuje s Tamtmem (A Bear – Sign with Tamtam). The app will help children to learn basic signs of Czech sign language through easy and entertaining game. Application is designed for tablets with Android and iOS, and is accessible freely at Google Play a App Store.

One month later, on November 27th, Tamtam was among panelist at a specialized conference „Early Care in International Context“ which took place on November, 27th. The goal was to evaluate quality and efectivity of early care service in Czech Republic, also in comparison with early care system in Italy and Great Britain. More pictures:

<http://arpcr.cz/tiskova-zprava-a-fotografie-z-konference/>



Country News - Finland

Welcome to Summerdays 28.6.-30.6.2019 in Piispala

The Finnish Association of Parents of Deaf and Hard of Hearing Children (The KLVV) is going to organize Summerdays on 28th-30th of June. The Summerdays will be held in Piispala, which is popular nature-, activity-, and traveling resort. Piispala is located in central Finland close by Kivijärvi- lake. The KLVV welcomes all Deaf or Hard of Hearing children and their families to the camp! If you are interested of joining to the camp in Finland, please do not hesitate to contact FEPEDA Secretariat!



Country News - Germany

Hear the sound with all senses - Mit allen Sinnen hören

In middle Hessen in Germany we organised for the first time a music workshop for hearing and hearing impaired pupils of 5th to 7th class of regular and special schools. During two weekends a group of 10 pupils was allowed to play and gain experience with classic as well as with modern instruments – some for the first time. Dr. Eva Mittmann, music teacher and therapist with a graduate in hearing impairments too, brought a wide range of fascinating exercises. The pupils discovered their voices, tried singing, played guitar, piano, boom whackers, self-made instruments and even painted the sounds of music. Mittmann stressed that hearing impairments should not be seen as a barrier to music. People with hearing impairments can have great musical talents too. Together with games on rhythm and performance the participants became good friends in a very short time. "The team-building was installed in such a short time that can only be evoked by the sound of music", mentioned Nicole Schilling, vice-chairwoman of German FEPEDA member Elternvereinigung hörgeschädigter Kinder in Hessen. Like the music workshop built up a great relation amongst the pupils there were also relations built between schools that supported the project. The same schools playing an active role in the process of in-clusion for hearing impaired pupils.

Country News - Lithuania

Operative primary support team for families in Lithuania

Since 2014, universal new-born hearing screening has been performed in Lithuania which allows early identification and rehabilitation of hearing impaired children. Association PAGAVA has been seeking that families with diagnosed children should receive support and information as soon as possible after the child is diagnosed.

In cooperation with Ministry of Health and Ministry of Education and Science, in 2016 an operative primary support team "Klausa" ("Hearing") was formed, including a representative of the parents' organization. Also, in

partnership with Lithuanian Educational Centre for the Deaf and Hard of Hearing, a leaflet was prepared to inform parents about the team "Klausa" and to encourage parents not to delay when their baby is diagnosed hearing impairment. When parents contact the team coordinator, it is agreed about the time and place of meeting with the team "Klausa".

At meeting with parents, the team specialists provide basic information on children deafness, language and communication development, state assistance to the baby and family, and answer parents' questions. Team "Klausa" is an early intervention aiming to maximize the baby's and the parents' potential; parents do not feel frustrated and lonely, they get information to be able to make necessary decisions in their child's life.



Country News - Lithuania continued

Summer events

Last summer was really exciting for deaf and hearing children, youth and their families in Lithuania. In June, more than 50 deaf and hard of hearing children got together in a summer camp to experience fascinating adventures and make unforgettable memories. Some of them determined to stay 10 days in a camp without parents for the first time. All the participants were learning self-sufficiency, tolerance and decision making skills by using informal and interesting educational methods. At the end of the camp they came up with a stronger self-confidence, richer luggage of knowledge and full heart of impressions as well as new friendships.

The biggest summer event - a traditional PAGAVA summer camp for the families with deaf and hard of hearing children - was exclusive this year. It was for the 20th time when families from all over the country were getting together to spend some valuable time with friends, relatives and other families by mixing it with meaningful rest on the beach of the Baltic Sea. Long-term partners of PAGAVA from special school for deaf from Belarus visited the camp with a group of young volunteers. Festive camp opening ceremony was fascinating with lots of congratulations and huge cakes dedicated for all the participants. The camp anniversary brought a lot of interesting and meaningful events together with traditional events such as families sport competition, Neptune feast etc. Families' summer camp united more than 400 participants.

Association PAGAVA pays a lot of attention for informal education of deaf and hard of hearing children which is very important during summer holidays. Therefore, members of association spent more active time in nature during organized hiking, rafting, picnics etc.

Country News - Romania

My name is Andrei Mare, I'm from Romania and here are my impressions of the Sinemorets camp after a stay of several good days. The camp was organized under the project „The Beauty of Difference” funded through



Erasmus+ programme and gathered people with hearing difficulties from four countries: Bulgaria, Lithuania, Poland, and Romania.

Each country had its interpreter in sign language who usually is also the leader of the respective team.

For me it was an great opportunity to get out of my comfort zone by traveling to a foreign country apparently different from Romania. Surprisingly as I know the Cyrillic alphabet (the Slavic letters) I noticed that many

Bulgarian words are similar or even identical to those from Romanian. I give you two

examples: garage and beach. The first word is "гараж" spelled „garaj", exactly like in the Romanian language and the other word is "плагж" spelled „plaj" with the Romanian equivalent being „plaja".

It was also an opportunity to improve my general culture with the usual expressions in each language of the invited countries, as well as their geography, history and local habits (Lithuanians are mad after basketball, Poles are proud of their composer Chopin, Bulgarians pride themselves with their rose jam, of which a thousand roses are needed to make a small jam jar).

The southern coast of Bulgaria is truly spectacular: cliffs ending directly into the sea, forest close to the coast, many natural site beaches / protejed area. Did you know that Veleka beach consists of a sand dune formed naturally by the alluviums of the Veleka river? And that it is stabilized by a flora which in turn supports a variety of fauna: birds, reptiles and turtles? I can say with dear heart that this camp had helped me to expand my mental horizons, to know our friends from the Romanian Association „Hear Life!" better, and by keeping the acquaintances in every participating country.

Even though the road was quite difficult for me, especially when I returned home, I would readily take part again in a similar event!

Andrei Mare

Country News - Spain

FIAPAS 40TH ANNIVERSARY

On its 40th anniversary, the Spanish Confederation of Families with deaf people (FIAPAS) organized a Scientific Congress with more than 250 participants, among ENT doctors, pediatricians, audiologist, speech therapist, teachers and families and professionals of the Associative Movement of Families of Deaf People.

Speakers of the highest national and international scientific level discussed on four symposiums about early diagnosis and intervention, advances in the treatment of deafness, benefits of binaural hearing on the information processing and the importance of the hearing brain development as key to language and literacy access.

Technology applied to diagnosis and treatment of deafness, adoption and evolution of the programmes of the early detection of child deafness, important role of research and genetic therapy, importance of the coordinated and interdisciplinary work, training of professionals and real inclusive education are some of the challenge that have been highlighted during the Congress.



Other initiatives on the 40th anniversary

During this year of anniversary, some other initiative have been adopted in order to put in value the role of the Families Associative Movement for the life of deaf persons and their families and to pay tribute to all those who have contributed to make FIAPAS a referent in the society for deaf people and their families

In order to show its gratitude to all people who have supported FIAPAS over the decades, FIAPAS launched the following video: https://www.youtube.com/watch?v=1_IGSsSQzws

FIAPAS also focused its annual awareness campaign on what being part of the Families Associative Movement means for all its members: families, friends, professionals, volunteer. <http://www.queloescuchetodoelmundo.com/>

Finally, FIAPAS paid tribute to those who have been part of FIAPAS history: the local and regional associations, public administration, private institutions... in a celebratory lunch with more than 150 participants.