



**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 ACTIVITY REPORT**

**European Federation of Parents of Hearing Impaired Children**



# **2019**



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FEPEDA is a non-governmental umbrella organization set up to represent associations of parents and friends of Deaf and Hard of Hearing children at a European level. It promotes the equal rights of Deaf and Hard of Hearing children and young people and their families across Europe in order to contribute to a fully inclusive European Society, where Deaf and Hard of Hearing children, young people and their families have equality of opportunity and participation.

FEPEDA was founded in 1990. The founding members of FEPEDA were the associations from Belgium, Denmark, France, Germany, Ireland, Italy, Luxemburg, Portugal, Spain, the Netherlands, and the UK.



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## **PRESIDENT's REPORT**

### **October 2018 – October 2019**

#### **Governing bodies meetings**

##### **1. General Assembly**

The General Assembly was held in Bucharest, Romania on 5<sup>th</sup> – 6<sup>th</sup> October, 2019. Eight members were present at the meeting.

The General Assembly had elections for the Management Committee. Each country has a right to have a representative in the Management Committee and, in line with the FEPEDA Constitution, is required to stand for re-election every three years. The following candidates were elected to the Management Committee: Antoaneta Yarickova (new representative, Bulgaria), Marta Höferová (new representative, Czech Republic), Marie O'Brien (new representative, Ireland) and Franziska Geiser-Bedon (Switzerland).

Darina Pantaleeva from Bulgaria was warmly thanked for her great work in FEPEDA during the last years.

Bosnia-Herzegovina was elected as a new Associated Member of FEPEDA.

The action plan for 2018-2019 was approved by the General Assembly the next Family Meeting being the main priority in 2019.

The Constitution of FEPEDA was reconfirmed by the General Assembly.



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## **2. Meetings of the Management Committee**

The Management Committee had meetings in spring (Basel, Switzerland in April 2019) and in autumn (Prague, Czech Republic in October 2019).



*Representatives of the Management Committee meeting in Basel, Switzerland*

## **3. Meetings of the Bureau**

The Bureau had two meetings – in February 2019 and in July 2019. Both meetings were held by skype.



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All the meetings of FEPEDA have been organised by a hosting country, together with the Secretariat. Meetings were held in locations, which are easy and cheap to access as well as in different parts of Europe so that as many members as possible can afford to send their representatives to the meetings.

The attendance by skype has also been encouraged.

The official language of all FEPEDA meetings is English.



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## Activities, Achievements and Projects

### 13<sup>th</sup> FEPEDA Family Meeting

The main activity this year was the FEPEDA Family Meeting – Eurofest Germany, which was successfully arranged in Dorfweil, Germany on 4<sup>th</sup> – 9<sup>th</sup> August. The camp gathered together families from seven European countries. The camp week provided with interesting program and activities for both children and adults. The main theme of the family meeting was “Empowering children and youth with hearing impairments and facing future challenges together”. This theme was handled from different perspectives during the camp week.

The Eurofest - project team had regular meetings before the camp. The camp was largely advertised amongst FEPEDA member countries.

The participants of the Family Meeting highlighted the importance of having family meetings on more regular basis suggesting having the next family meeting already in 2021.



*Participants of the Family Meeting visiting European Central Bank*



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## **Sharing information amongst members and families**

For information sharing FEPEDA uses various channels like website, Facebook, WhatsApp and e-mail. Two Newsletters have been published after October 2018 – one in December 2018 and the other one in June 2019. Each Newsletter has a special Country news – section, which provides a good opportunity for sharing news and best practises between the member countries.

## **Projects**

FEPEDA has started planning / launched different projects this year to make FEPEDA more known at member/family level and to support families in its member countries.

### **Photo campaign**

The idea of the photo campaign is to support the children and youth with hearing impairments. The purpose 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 in a planning phase aiming to be launched later in 2019.

### **Family camp exchange**

The idea of the family camp exchange is to encourage FEPEDA member countries to invite families from other countries to their summer camps. Members had the possibility to use FEPEDA's channels (like Facebook, Newsletter) for advertising their camps.



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## Penpal-project

The Penpal-project was launched during the FEPEDA Family meeting. The idea of this project is to offer children and their families peer support across borders, no matter in which country you live in. The project will be developed further.

## Advocacy and cooperation with other organizations

Advocacy work and cooperation with other organizations has been active. At European level FEPEDA has campaigned together with other organizations in many issues. One of this year's main achievements has been the European Accessibility Act, which was finally voted in the plenary session of the European Parliament in Strasbourg on 13<sup>th</sup> March.



*Members of the Platform celebrating the approval of European Accessibility Act on 13<sup>th</sup> of March*



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## **European Disability Forum ([www.edf-feph.org](http://www.edf-feph.org))**

In May André Cuencá attended the General Assembly of European Disability Forum (EDF) being also FEPEDA's candidate to the EDF Board. The elections for one open seat took place at the General Assembly.

FEPEDA has on regular basis contributed to different documents issued by EDF, focusing on the needs of families with deaf children and in deaf persons.

## **European Platform of Deafness ([www.epdhdb.eu](http://www.epdhdb.eu))**

The president and the secretary attended the meeting of the European Platform of Deafness. The meeting was held on 13<sup>th</sup> of March in Barcelona, Spain.

The Platform has campaigned together e.g. for the accessibility in the European elections, which took place in May.

## **GPODHH ([www.gpodhh.org](http://www.gpodhh.org))**

The President and Secretary General have been active in GPODHH attending its meetings via skype.

The president and the secretary met LeeAnne Seaver, the chair of GPODHH in Helsinki, Finland on 30<sup>th</sup> April. On the agenda was the future cooperation between FEPEDA and GPODHH.

## **FCEI-conference in 2020 ([www.fcei.at](http://www.fcei.at))**

Plans for the next FCEI-conference to be held in Bad Ischl, Austria in 2020 have been started. FEPEDA has shared information on this event through its channels.



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## WHO ([www.who.int](http://www.who.int))

At the Management Committee meeting in April FEPEDA decided to apply for the membership of WHF (World Hearing Forum).

On the World Hearing Day 3<sup>rd</sup> of March FEPEDA launched a press release on early identification and intervention for hearing loss.



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Could you be missing out?

Check your hearing!

An app to check your hearing.  
World Hearing Day 2019

PRESS RELEASE

World Hearing Day 2019. Early identification and intervention for hearing loss.

(Helsinki, 3.3.2019) On the World Hearing Day 2019, the European Federation of Parents of Hearing Impaired Children (FEPEDA) would like to join World Health Organization's (WHO) message and draw attention to the importance of early identification and intervention for hearing loss.

As WHO points out, hearing loss is on the rise and unless action is taken, by 2030 there will be nearly 630 million people with disabling hearing loss and by 2050 the number could rise to over 900 million<sup>1</sup>. Data from studies in middle- and high-income countries analysed by WHO indicate that among teenagers and young adults aged 12-35 years, nearly 50% are exposed to unsafe levels of sound from the use of personal audio devices and around 40% are exposed to potentially damaging levels of sound at entertainment venues<sup>2</sup>.

It is important to know that your child may have a hearing loss if he/she doesn't respond to sounds, cannot understand what you say properly, has delayed or improper speech development, suffers repeated episodes of pain in or blockage of the ear. In these cases, you should visit the specialist doctor in order to assure an early detection and intervention.

Furthermore, FEPEDA reminds to EU State members that it is essential to develop and implement neonatal hearing screening programmes as well as programmes afterwards, in order to assure that every child, every person with a significant hearing loss is early detected. However, detection and diagnosis must be followed by intervention and access to high-quality assistive hearing technologies, including hearing aids, hearing implants and other assistive devices, as part of universal health coverage.

FEPEDA, established in 1990, is the main platform of representation of families with deaf and hard of hearing children in Europe.

<sup>1</sup> <https://www.who.int/deafness/world-hearing-day/WH-D-2019-infographic.pdf?ua=1>

<sup>2</sup> [http://www.wpro.who.int/vietnam/mediacentre/releases/2015/hearing\\_loss\\_pr/en/](http://www.wpro.who.int/vietnam/mediacentre/releases/2015/hearing_loss_pr/en/)



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## Administration

The Secretariat of FEPEDA is currently in Finland following the current presidency. The secretarial work has been taken care by a part-time Secretary, who has been working closely with the President and the Bureau members. The Secretary was also a member of the Eurofest-project team assisting with all the family meeting preparations.