



***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 Newsletter 2/2023

Greetings from the President

Two main events on the second semester of 2023:

- FEPEDA Annual General Assembly
- Participation to WHF stakeholders meeting

General Assembly was held in Sofia – Bulgaria in October 2023 (and online for members who couldn't travel).

There was a good participation of FEPEDA member representatives from the organisations of the various countries of Europe. The members of Bulgarian organisations attended to the GA meeting and there were fruitful exchanges. The meeting was very well organised by Bulgarian organisation providing an excellent welcome to members.

Exchanges between members highlighted the actions of the members for deaf and hearing-impaired children (see more details in the following pages).

The President of FEPEDA represented FEPEDA to World Hearing Forum stakeholders meeting in Geneva on November 27 and 28. The main theme was to exchange on the way to suppress the barriers and to define strategies for changing people's perceptions of hearing loss (see more details in the following pages).

FEPEDA thanks a lot the members for their involvement to defend the rights and to improve the quality of life of deaf and hard of hearing children and their families, with respect for the way of communication and the method of education they have chosen.

Happy new year.

Content

Greetings from the President
WHF meeting
FCEI
Previous FEPEDA meetings
Upcoming FEPEDA meetings
Country news
Czech Republic
Sweden
Switzerland

André Cuenca, President of FEPEDA



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World Hearing Forum (WHF) stakeholders meeting on November 27 and 28, 2023

FEPEDA President participated to WHF stakeholders meeting on November 27 and 28, 2023 at World Health Organisation in Geneva - Switzerland

The forum is composed of around 180 members from 57 countries: associations of the deaf and their families, professionals, universities/researchers, etc.

More than 200 organisations were represented in this meeting (members and organisations involved in hearing area).

Exchanges were in English, with subtitles in English and several languages, and translation in English Sign Language

The main objectives were:

- To exchange on the importance of barriers and strategies for changing people's perceptions of hearing loss
- To inform stakeholders about the work and initiatives of the WHO Ear and Hearing Care Program
- To identify opportunities for integrating ear and hearing care into lifelong public health initiatives, including primary health care.

The main topics issued from the presentations and exchanges were:

- 450 million people worldwide suffer from hearing loss and this figure is expected to rise to 700 million by 2050: 20% only of people with hearing loss receive care. In developing countries, deafness is not a priority.
- Main barriers:
 - Invisible disability and ignorance of this type of disability
 - Lack of awareness among parents, politicians and the social environment
 - Public acceptance problems
 - Stigmatisation, especially of deaf and hard-of-hearing teenagers
- Main actions and strategies:
 - Action on the 4 Ps: Public, Provider, Policy, Professional
 - WHO has worked on tools and guidelines, in particular for early and life-long screening (evolution) – HearWho tool to assess the level of hearing
 - Changing attitudes and perceptions of deafness
 - Training of those involved: education, health, administration, etc.
 - Taking the whole child into account, including the family
 - Improving the quality of education for people with hearing loss
 - Communication and advocacy: videos, social networks, World Hearing Day
 - Making listening to music safer to avoid damage to hearing
 - Working with World celebrities: actors, politicians, musicians, etc.



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- Working groups during the meeting:
 - Main barriers on social perceptions of hearing loss
 - Approaches and actions to help to change mentalities and social perceptions



Participants to WHF stakeholders meeting



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FCEI (Family Centred Early Intervention) Conference

The 6th International Conference on Family Centred Early Intervention for Children who are deaf or hard of hearing [FCEI 2024](#) will be held on May 2024, 15 to 17, in Bad Ischl -Austria, under the motto 'Connect, Communicate and Collaborate'. The Austrian member will be one of the keynotes presenters. **Registration is open.**

[Global Coalition of Parents of Children who are Deaf or Hard of Hearing \(GPODHH\)](#), which plays an important role in planning the programme for the preconference, is having meetings once every two months.

Previous FEPEDA meetings

A Bureau meeting was held on September 27, 2023. Members of the Bureau are:

André Cuenca as new President of FEPEDA
Antoanetta Yarichkova as General Secretary (since October 2023)
Sari Paloposki as Vice President
Carmen de Lamo as Vice President
Cosmin Brasov as Vice President
Franziska Geiser-Bedon as Treasurer

General Assembly (GA) meeting was held on October 21, 2023, in Sofia – Bulgaria and online. **A Management Committee (MC)** meeting was held before the GA meeting, on October 20, and another **MC** meeting after the GA meeting, on October 21.

The first Board meeting was attended by 17 participants from 14 European countries. In addition to FEPEDA members, members of the Bulgarian association also attended the GA meeting. The Bulgarian association provided an excellent welcome to the participants and the two days meeting were very well organised.

In addition to the usual items to be dealt with at a GA meeting, such as finances, the budget, the annual report and the action plan, discussions took place on various subjects presented by the country representatives:

- Programme of support to families by Spain Exchanges in multidisciplinary approach experience in care: presented by Czech Republic member on MC meeting in Rome but not enough time to exchange between members.
- Educational assistance/support deaf/hard of hearing children (oral and sign language support) in mainstream schools and universities by Italy
- (see presentation in English and video in Spanish with English subtitles). Link to the video: https://youtu.be/cF2qTWae2zg?ist=PLsuxCjQWSODxkABsxWFbHWhEfgkuLWT_q
- The members representing the following countries were elected: Finland, France, Romania, Spain and Sweden.



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Discussions were held on the development of projects for families. FEPEDA members also discussed ways of communicating more effectively about FEPEDA's activities and the impact they have on the day-to-day lives of deaf and hard-of-hearing children and young people and their families. Some ideas were pre-defined and will be developed in the Bureau and MC to be held in 2024.

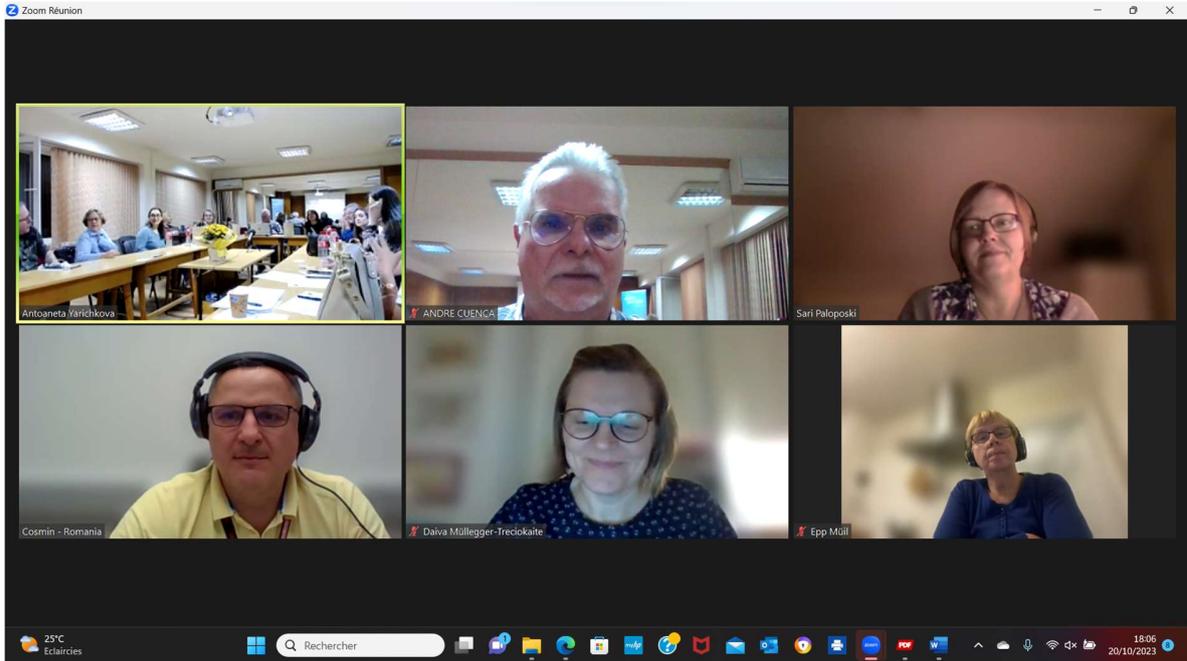
At Bureau level, the two Vice-Presidents at the end of their term of office were re-elected and the Bulgarian representative was elected as General Secretary.



FEPEDA members in Sofia



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FEPEDA members online

Upcoming FEPEDA meetings

Bureau meeting virtually by Zoom will be held in January 2024

Management Committee meeting on April 26 and 27, 2024 in Goteborg – Sweden

Bureau meeting virtually by Zoom will be held in September 2024

General Assembly meeting in October 2024 in Madrid -Spain



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Country News

Czech Republic

It has been a few exciting months for us. We organized several events for deaf children and their families: theater performances with interpretation, zoo visitation with programs, etc. Before the **International Week of the Deaf** we hosted an **annual garden celebration** for our client families.

Two main topics of our specialized journal consisted of **acquired hearing loss and inclusion**. We published articles and interviews with experts and parents focusing on these topics. Another important interview was about the problem of bullying in schools with a Czech expert on bullying prevention, Dr. Michal Kolář. On the occasion of the 109 years anniversary of the birth of an **internationally famous Czech deaf ballet dancer**, we published an article celebrating this **icon and role model called Mobe Urbanová**. Our next Winter edition of the journal will be covering the topic of **being deaf and looking "different"** - which includes living with Treasher Collins Syndrom, Goldenhar syndrom, microtia, atresia of auditory meatus and other conditions.

Our **social workers** registered a higher level of requests regarding social benefits for low income people (for housing, material need benefit, etc.). because of the inflation and overall current social situation - more and more people need these benefits. Refugees from Ukraine with disabilities do not have the access to benefits as Czech citizens with disabilities so helping them getting support tends to be more difficult because of more barriers.

Early intervention service continues the cooperation with medical professionals outside the organization - round tables and case consultations. VRA (visual reinforcement audiometry) examination proves to be very useful.

In October we celebrated the 10th anniversary of the Pardubice workplace with an Open Day, when the **social activation service (SAS)** was launched at this workplace (last year in November we celebrated the 10th anniversary at the Ostrava workplace, next year it will be the 15th anniversary of the Prague workplace). The social activation service is being transformed especially by new family situations, when the necessity of multidisciplinary cooperation becomes more and more evident, not only in the field of hearing impairment, but especially regarding psychological support. Specifically, there is an increase in families where the parents break up or the situation changes due to the adult's health condition. With this, of course, among other things, the financial security of the family changes. Also we still sometimes have new client families with a child who is 5, 6 or more years old and a clear



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diagnosis of hearing loss has not yet been established, and at the same time functional communication has not been set up. This is an ongoing challenge we keep addressing.



Garden party



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Sweden



National Association for Deaf, Hard of Hearing Children and Children with Language Impairment

Patron: Her Majesty the Queen

DHB is for many of our members an association where you can meet other families, have fun and exchange experiences. In our two biggest districts DHB West and DHB East we have a lot of activities throughout the year. We have staff employed to plan and organize the activities and apply for funding to make the activities cheaper. Still a lot of the work is done voluntarily by our members. Parents and youth. Some of our coming activities for 2024 are:

- Ice hockey and skating school
- Swimming-classes
- A language trip to Great Britain for youth that are hard of hearing
- Skiing weekends and skiing schools
- Sign language courses for families and relatives
- A trip to Legoland in Denmark
- The amusement park Liseberg in Göteborg
- Summer family camp
- A trip to the ZOO in Borås
- Youth weekend with Escape-room

On October the 20th – the DLD Awareness Day, DHB together with three other organisations were published in the magazine “Specialpedagogik” – Special Education.

The school must understand the challenges of multilingualism

Schools know far too little about multilingual students, language impairment/DLD and linguistic variation due to exposure to a new language, according to a call for DLD Awareness Day.

More and more students in Sweden are multilingual. About a third of children aged 0 to 5 grow up with at least one parent whose mother tongue is not Swedish.

Research shows that multilingual children with language difficulties are at risk of:

- wrongly receiving a language disorder diagnosis
- not receiving a diagnosis because their language disorder/DLD is not detected.

The school must therefore increase its knowledge of multilingualism and language impairment/DLD as well as how children's exposure to language affects vocabulary and use of language.



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In linguistic tests, the results of multilingual children are usually compared with the results of children whose parents speak the majority language. This comparison can be misleading and lead to an incorrect diagnosis of language disorder. Multilingual people use different languages in different contexts, which means that vocabulary often differs from language to language. In addition, it is common for children who are multilingual to switch between two languages in the same conversation. The standardized tests used to examine the child's use of language do not compensate for this fact. Overall, this increases the risk that multilingual children who do not have a language disorder/DLD will still receive a diagnosis.

Conversely, myths surrounding multilingual children lead to children with language impairment/DLD not being diagnosed. A persistent myth is that multilingual children have delayed language development. The language difficulties that are noticed are therefore blamed on bilingualism, which means that multilingual children are not investigated for language impairment/DLD.

Language impairment/DLD is always present in all languages a person uses. However, a language disorder can express itself differently in different languages as sound systems, grammar, words and social rules differ between languages. A student with a language disorder/DLD may have less grammatical difficulties in one language than in another. However, we know that a student with a language disorder/DLD has a lower linguistic ability than peers in all the languages he uses.

Language impairment/DLD also does not need to be heard in speech, which can make a student with a language impairment "fly under the radar". The difficulties may instead lie in the understanding of what someone says and the use of the language. A student with dyslexia, ADHD or autism may also have a language disorder/DLD but is not always investigated for this. Girls are investigated for language impairment/DLD less often than boys, despite the fact that roughly the same number of girls as boys have language impairment/DLD.

Exposure to language is another factor. Children who only use Swedish as a school language but are exposed to another language in the home environment can perform lower in language tests than peers in general. Other children have a so-called mixed language dominance with different linguistic strengths in different languages. Language impairment/DLD must be tested in the language that the child uses most, i.e. the language that dominates.

Language impairment/DLD affects learning in all school subjects. Multilingual students who are perceived to have language difficulties at school need to be given the opportunity for a professional assessment and investigation by a speech therapist. It is therefore particularly important that schools with a high proportion of multilingual children invest in increasing their knowledge of multilingualism and language impairment/DLD.

Berit Robrandt Ahlberg, chairman of the Aphasia Association/Talknuten
Jan Höglund, chairman DHB
Albert Telon, chairman Young people with language disorders
Kerstin Wiström, chairman of the Speech-Language Association



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Some facts about language disorder/DLD:

- 7–8 percent of all students have a language disorder/DLD.
- A language disorder affects learning in all school subjects.
- Speech therapists investigate language disorder/DLD.
- Diagnosing language impairment/DLD in multilingual children can be improved by using, for example, non-word repetition and dynamic assessment, and that one can also advantageously assess processing speed, auditory discrimination and executive functions.



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Switzerland



Activate instead of compensate

22nd “Bodenseeländertagung” conference of the regions around Lake Constance from April 20 to 22 in Zurich

In mid-April, educational experts from southern Germany, Austria and Switzerland met in Zurich for a three-day conference. The **Swiss Association for parents with hearing impaired children (SVEHK)** was present with a booth and introduced itself to the attendees with a short presentation.

The BOTA (www.bota2022.ch), as the “Bodenseeländertagung” is abbreviated, takes place every three years in the regions of the three countries around Lake Constance. The cross-national exchange of expertise takes up current topics in the fields of education and upbringing of children and adolescents with a hearing impairment. The aim is to promote the professional field in order to safeguard the interests of people with hearing disabilities and to provide them with the best possible opportunities for development.

In addition to the varied program of lectures and workshops, the Info Market – at which the SVEHK was represented by President Agi Gasser and Board Member Liselotte Oesch – offered opportunities to exchange information.

A moderator duo skillfully led through the conference in sign language. Translations into spoken, written and sign language facilitated communication and worked very well.

Together we are strong

On the second day of the conference, Agi Gasser introduced the **Swiss Association for parents with hearing impaired children** to the attendees in a short presentation. She emphasized that the SVEHK is neutral, tolerant and open to different methods of communication. It is important that the child can communicate and that the whole environment of the child is supported. The President took the opportunity to talk about the vision and goals as well as national and regional activities of the SVEHK. For parents, mutual support is very important, but also networking with all stakeholders in the deaf and hearing impaired community. With its annual networking at the beginning of the year, the SVEHK ultimately pursues the same goal as the organizers of the BOTA: to strengthen the common commitment on behalf of children with a hearing impairment.



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Our booth at the BOTA

Successful parents' conference in Wetzikon

The Swiss Association for parents with hearing impaired children conference took place in Wetzikon ZH for the first time at the end of October 22. While the parents attended talks and workshops, the children were out and about in the Zürcher Oberland in groups with their carers. Everything went off fantastically well thanks to the clever organisation in the background and significant support both from within the association and from outside it.

“Grüezi, bonjour, buongiorno,” the moderation team welcomes the large audience in the room. The motto for the conference is “In the midst of life – the family is at the heart”.

Inputs for the whole weekend

The opening presentation by Professor Nils Jent and Petra Kopf, entitled “Strong together – actual inclusion” resonates for a long time and fits in perfectly with the workshop topics: subjects such as language development, ADHD diagnosis or harassment are just as important as testimonies from young people with hearing impairment or pleasant exchanges on the parents' sofa.

The atmosphere at the parents' conference can hardly be described. It is a lively coming together, groups of people gather everywhere to talk to one another. There is space for all languages, whether German, French, Italian, sign language in the appropriate language, cued speech, etc.

What is happiness?

33 childcare workers look after 120 children and young people across two days. This gives their parents time and space for the necessary exchange. All too soon, the weekend is over. Everyone meets on Sunday for the final presentation. The topic is “Happiness”.

“Well-being isn't a one-off exercise,” the speaker says. The fact that the parents' association is able to make a contribution to the families' well-being with this weekend is only possible thanks to everyone working in the foreground or the background. Our heartfelt thanks for your invaluable work.



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www.svehk-elterntagung.ch



SVEHK childcare workers



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Happy New Year