

# Annual Report 2023



An international and independent non-profit making Society for physicians, health professionals, scientists, and students with research and/or clinical interest in Paediatric Neurology.

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## EPNS President's welcome

I am delighted to share with you the European Paediatric Neurology Society (EPNS) Annual Report for 2023. This has been another outstanding year for the EPNS, as we have strengthened our established activities, explored new ideas and increased our advocacy efforts, thus ensuring the EPNS is the key voice for paediatric neurology in Europe and beyond. Let me first, however, on behalf of the EPNS, offer our heartfelt condolences to those in our Society who have lost loved ones in regions involved in conflict. The EPNS expresses in particular concern for medical professionals, scientists and public health workers caring for children with neurological diseases threatened in the Ukraine by the ongoing invasion of Russia and the conflict in Israel/Gaza triggered by the brutal attacks and kidnappings of civilians by the terrorist organisation of Hamas leading also to indiscriminate suffering of the population in Gaza and in particular children.



Photo: Kevin Rostasy  
EPNS President

This year, members of the EPNS Board members reflected on the goals of the EPNS and consequently a clear EPNS Mission Statement has been developed and published on the EPNS website, which you will also find on the next page.

There are many highlights from 2023 contained within the report, including of course the 15th EPNS Congress in Prague which delivered an outstanding scientific programme and excellent networking opportunities. I hope that those of you who were able to join us in Prague agree, and that attending has supported your continuing medical education and improved care for your patients. I congratulate my colleagues who were involved in organising the event, especially Professor Pavel Kršek, Professor Barbara Plecko and Dr Kveta Janoušková.

During the EPNS Congress in Prague, I was privileged to be a part of the EPNS Honorary Member award ceremony for 2023. EPNS honorary members are described in our constitution as 'persons the society wishes to honour for outstanding distinction in the field of paediatric neurology.' This is not an honour which the EPNS Board bestows lightly, and the 2023 recipients of EPNS honorary membership join an illustrious list of respected colleagues who have made significant contributions to our field. I extend my sincerest congratulations to five esteemed colleagues.



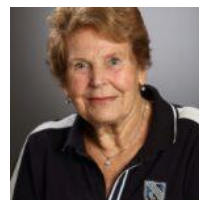
Coriene Catsman-  
Berrevoets  
(Netherlands)



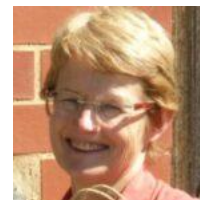
Linda de Vries  
(Netherlands)



Mary King  
(Ireland)



Sona Nevsimalova  
(Czech Republic)



Maja Steinlin  
(Switzerland)



Without a break, plans are now full steam ahead for our next EPNS Congress, which will take place in Munich Germany on 8-11 July 2025, and I have the privilege to be part of the Local Organising Committee which is Chaired by Professor Florian Heinen. It seems a long way away, but please be sure to save this date in your calendar!

Many congratulations to the Barcelona team who were successful with their bid and have been selected to host the 17<sup>th</sup> EPNS Congress on 14-18 September 2027.

In addition to our EPNS Congresses, by reading this EPNS Annual Report you will appreciate that the EPNS continues to grow from strength to strength, and learn about our many educational, scientific, advocacy, Society Journal and Young EPNS developments and activities.

The EPNS has a strong educational focus and 2023 has been no different with the recent roll-out of the EPNS Moodle, our ongoing webinars, supporting EPNS fellowships & EPNS Visiting Teachers, training courses taking place in Latvia and Kazakhstan, and the important sitting of the first EPNS Exam. I hope you will be able to get involved in our planned educational activities for 2024.

The EPNS Advocacy and Advocacy Committee is a relatively new committee, but has made a massive impact already, with many activities you can read about in this report. I urge you in particular to read about the Intersectoral Global Action Plan on epilepsy and other neurological disorders (IGAP). The IGAP implementation will be a major focus for the EPNS in the coming years ahead.

The Young EPNS (YEPNS) has become an integral and established part of the Society. Their enthusiasm is valued and with pleasure, I can announce that each YEPNS Working Group is now aligned to an EPNS Committee. More details are shared in the YEPNS update in this annual report.

I would like to welcome our many new members and thank all EPNS Board members, EPNS members and collaborators for your continued support and trust in the Society. The strength of our Society has always been a result of the input of our incredible members, and I am thankful for everyone's support and contributions.

I hope you will have the opportunity to attend one of our EPNS events in 2024, such as one of the EPNS training courses in Ferrara, Italy, the EPNS Masterclass in Cambridge, UK and our well established EPNS Research Meeting in Ljubljana, Slovenia.

I look forward to another busy year in 2024 at the EPNS and I wish you and your families good health and success.

**Best wishes**

**Kevin Rostasy, EPNS President**



## EPNS Mission Statement

The EPNS as an international and independent non-profit making Society for physicians, health professionals, scientists, and students with research and/or clinical interest in Paediatric Neurology. Our mission is to promote excellence in patient care, research, and education to improve the neurological outcome of children and young people in Europe and across the world.

The EPNS goals are outlined as follows:

1. Advocate for easy and equitable access to the highest standard of patient care in neurology for children, young people, and support for their caregivers.
2. Promote excellence in education and training, providing a comprehensive learning environment in paediatric neurology to students, trainees, and qualified professionals in all stages of their career.
3. Foster, expand and support science and clinical research in paediatric neurology bringing together the best clinicians and scientists in the field.
4. Engage with policy makers, patient groups, and the general public to promote best practice from fetal life to the young adult.
5. Nurture multidisciplinary and international collaborations to address the diagnosis and treatment of children and young people with neurological disorders.
6. Improve understanding, respect, inclusion, and support for all individuals affected by long term neurological sequelae providing appropriate management and rehabilitation.

Education, Promotion, Networking, Science  
for Paediatric Neurology



## EPNS Board Members 2022-2026

Nadia	Bahi-Buisson	France
Dewi	Bakker	Netherlands
Sandra	Bigi	Switzerland
Anne-Marie	Childs	United Kingdom
Maria Roberta	Cilio	Belgium
Dana	Craiu	Romania
Rob	Forsyth	United Kingdom
Lucia	Gerstl	Germany
Kathleen Mary	Gorman	Ireland
Anna	Jansen	Belgium
Altynshash	Jaxybayeva	Kazakhstan
Ilona Anna	Kopyta	Poland
Pavel	Kršek	Czech Republic
Lieven	Lagae	Belgium
Ming	Lim	United Kingdom
Jean-Pierre	Lin	United Kingdom
Ignacio	Malaga Diéguez	Spain
Francesco	Muntoni	United Kingdom
Finbar	O'Callaghan	United Kingdom
Jasna	Oražem Mrak	Slovenia
Barbara	Plecko	Austria
Kevin	Rostasy	Germany
Thomas	Sejersen	Sweden
Agnese	Suppiej	Italy
Inga	Talvik	Estonia
Monica	Vasconcelos	Portugal
Federico	Vigevano	Italy
Michel	Willemsen	Netherlands
Dilek	Yalnizoglu	Turkey
Dimitrios	Zafeiriou	Greece
Sameer	Zuberi	United Kingdom

## EPNS Treasurer & Finance Report

I am pleased to report that the EPNS continues to successfully finance its ongoing activities.

Organised by the **EPNS Scientific and Research Committee** in conjunction with Intercongress and the Local Organising Committee, it was a pleasure in June 2023 to host our 15th EPNS Congress in Prague with more than 2,000 attendees. The event was subsidised in several different ways by the EPNS and was a great success for education, research, and networking opportunities for paediatric neurologists from around the world.

The **EPNS Education and Training Committee** has also had a busy year and of course, in the tradition of the EPNS, we continue to host and financially subsidise our 3-year rolling EPNS training programme. After 2 years of virtual courses, finally Riga in Latvia were able to host an in-person event in their country which proved to be a great success. In addition, the EPNS supported the Central Eurasia workshop in Kazakhstan, and received excellent feedback. A new area for this committee was the introduction of the EPNS Exam, which as a one-off special offer, was offered to candidates at a much-discounted registration fee. This year the EPNS invested funds into the roll-out of the EPNS Moodle which offers our EPNS members access to a whole plethora of learning resources. Funds continue to be invested in online ways for the EPNS to provide educational opportunities for our members, such as the virtual platforms for our Monthly Webinars, Online Training Courses, Journal Clubs, Case Discussions, etc. It is always a great pleasure to fund the EPNS Fellowships (8 in 2023) and EPNS Visiting Teachers (2 in 2023) where we enable career changing experiences to take place.

The still relatively new **EPNS Advocacy and Collaboration Committee** has made great progress and the EPNS has been able to fund several fruitful collaborations and visits to raise the voice of child neurology.

The **EPNS Guidelines Committee** has become more established, and funds have been used to develop guidelines in for example, paediatric epilepsy.

The **EPNS Finance, Membership, PR and Website Committee** and especially also our Administrative Team (Sue Hargreaves and Mel Knowles) play a central role in running our Society and are happy to announce that membership is growing at a steady pace over the past years. We continue to strive to keep our administrative costs to a minimum.

Altogether, I can report the EPNS has a healthy financial situation with adequate funds domiciled in a safe bank account at a Private Bank in Germany. Our system for detailed budgeting for our five main committees (see above) allows us to monitor all financial matters closely and to let the EPNS flourish for the benefits of its members and all their activities in the field of child neurology.

**Best wishes**

**Michel Willemsen, EPNS Treasurer**



Photo: Michel Willemsen  
EPNS Treasurer





## EPNS Scientific & Research Committee

### 15<sup>th</sup> EPNS Congress 2023

The 15th EPNS Congress took place at the Prague Conference Centre, Prague, Czech Republic on 20-24 June 2023, hosted by Pavel Kršek. The theme was: 'from genome and connectome to cure.' The programme was developed with innovative platform sessions and distinguished invited speakers. An EPNS record breaking 746 abstracts were submitted and with pleasure together the Czech national society, the EPNS Congress awarded 30 bursaries.

It was anticipated that the Prague EPNS Congress, the first fully in-person after the pandemic, was going to be a special event and having examined the evaluation report, it didn't disappoint! With more than 2,000 participants, the Congress surpassed all expectations. The Congress presented a scientifically stimulating programme with an outstanding Aicardi Award Lecture, three full days of educational sessions, networking, interaction, updates from our industry partners, and the EPNS Academy & Highlights in Paediatric Neurology as a grand finale.



Photo: Barbara Plecko  
Chair EPNS Scientific &  
Research Committee

**The Pre-Congress Symposium** took place on 20 June 2023 in Prague, focusing on "Drug-resistant epilepsy in the 21st century: From molecular mechanisms to precision therapies". This too proved to be a successful event with 528 participants organised in collaboration with EpiREC, ERN-EpiCARE and the ILAE. Congratulations on this achievement.

I thank all speakers, my colleagues on the EPNS Board, Local Organising Committee (LOC) and the YEPNS for all their hard work in planning the event and developing a stimulating scientific programme. Special thanks must be expressed to Pavel Kršek and Kveta Janoušková for their dedication in organising such a wonderful event. Thank you also to those of you who were able to join us in sunny Prague and I hope you have found the event supported your continuing medical education and daily work.

You can visit the photo gallery to relive the Prague EPNS Congress:

[CLICK HERE](#)

Or watch and enjoy this short video

<https://youtu.be/LsAwEHBEzkc> :





**Congratulations to our EPNS Congress award winners:**



**4<sup>th</sup> Aicardi Award:** This award is in partnership with MacKeith Press. Francesco Muntoni from the UK was presented with this prestigious award during the opening ceremony 20 June 2023. The wonderful lecture was entitled “Lesson learned developing novel therapies for childhood neuromuscular disorders” and was one of the highpoints of the EPNS Congress 2023.



**EJPN Paper of the Year Award 2023 (left picture above):** This newly established prize was also presented at the Opening Ceremony to Kirsten Schouwstra from the Netherlands for the article ‘Application of the Scale for Assessment and Rating of Ataxia in toddlers’

**Outstanding Abstract Award 2023 (right picture above):** Leo Arkush from Israel received this award during the Opening ceremony for the abstract ‘Long-term cognitive consequences of self-limited epilepsies of childhood’

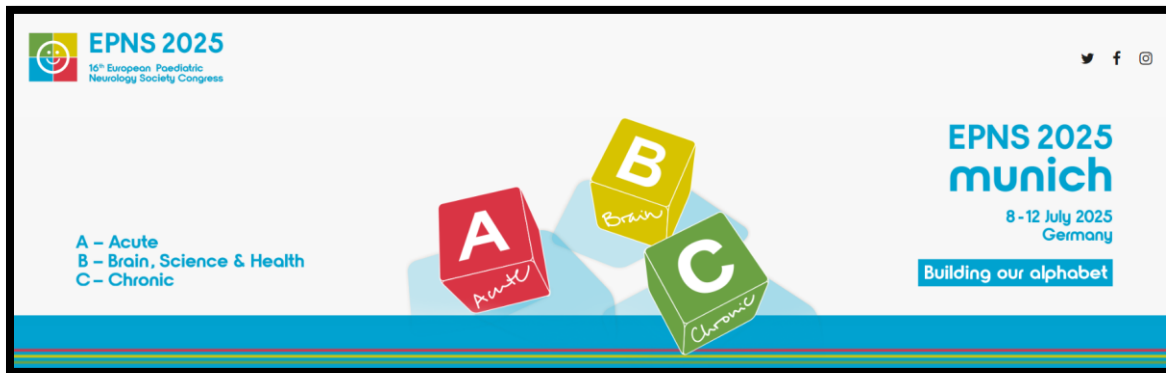
**Best Oral Presentation 2023:** Nina-Maria Wilpert from Germany for the presentation 'Paediatric de novo movement disorders in the context of SARS-CoV-2'

**Best e-Poster Presentation 2023:** Juan Dario Ortigoza-Escobar from Spain for the e-Poster 'Seven new cases of developmental encephalopathy 64 associated with RHOBTB2 variants and a review of literature'.



**EPNS Congress 2023: learn more:**

- Book of Abstracts can be viewed: [CLICK HERE](#)
- Speaker authorised presentations can be viewed in the members' area of the EPNS website: [CLICK HERE](#)



## 16th EPNS Congress 2025

Plans are now full speed ahead for the next EPNS Congress which will be hosted by the Gesellschaft für Neuropädiatrie (GNP) in Munich, Germany on 8-11 July 2025.

For the 2025 EPNS Munich Congress, Paediatric Neurology will be classified into:

**A** for acute

**B** for Brain, Health & Science

**C** for Chronic.

In 2025, be part of this unique ABC format to learn, teach (and be taught), meet and exchange ideas on an international stage. Be sure to save the date!

## 17th EPNS Congress 2027

Sincere congratulations to the Barcelona team for presenting an excellent bid in June and they have been selected to host EPNS Congress 2027!



## EPNS Research Meeting 2024

# EPNS Research Meeting

## 17-18 October 2024

### Ljubljana, Slovenia



Attend 2 of the 8  
Working Groups

- Ataxia
- Autoimmune Inflammatory Diseases
- Epilepsy
- Movement Disorders
- Neonatal Neurology & Developmental Neurology
- Neurometabolics
- Neuromuscular Disorders
- Paediatric Stroke

Forum for experienced and young researchers  
in Paediatric Neurology  
to collaborate & present their work, ideas, results.

For more information visit the EPNS website <https://www.epns.info>



The next EPNS Research meeting is taking place in Ljubljana, Slovenia on 17-18 October 2024 and hosted by Professor Zvonka Renner Primec and Dr Jasna Orazem.

EPNS Research Meetings are held every 2 years, in alternate years to the EPNS congresses.

Child Neurologist researchers at all stages of their career are welcome for presenting their research, collaborating, and building networks.

Participants will attend 3 plenary sessions plus 2 of the 8 Working Group sessions:

- Ataxia
- Autoimmune Inflammatory Diseases
- Epilepsy
- Movement Disorders
- Neonatal Neurology & Developmental Neurology
- Neurometabolics
- Neuromuscular Disorders
- Paediatric Stroke

30 Bursaries will be granted upon individual application. Available to fully paid up EPNS members only.

Two Research prizes of 2,500 Euros per person will be awarded to young neurologists who present outstanding, innovative ideas in research in Paediatric Neurology.

You will find more information here <https://www.epns.info/epns-research-meeting-2024/>

## EPNS Research Meeting 2026



Professor Dimitrios Zafeiriou will host the 9th EPNS Research Meeting which will take place in Thessaloniki, Greece. The dates in 2026 will be announced later next year.

**The EPNS collaborates with the following societies and organises joint sessions at Congresses.**

### European Academy of Childhood Disability (EACD)

With pleasure, the EPNS will participate in a joint session at EACD 29 May-1 Jun 2024, Bruges. The EPNS EACD representative is Ilona Kopyta.

### European Academy of Neurology (EAN)

The EPNS is looking forward to being part of EAN 29 Jun-2 July 2024, Helsinki

### International Child Neurology Association (ICNA)

Upcoming meeting: ICNA Congress Cape Town 4-10 May 2024 and the EPNS is honoured to have been invited to participate in the new Grand Rounds format.

### Young EPNS (YEPNS)

With pleasure, I can announce that this committee is now aligned with the YEPNS Research and Career Working Group, who will be involved with the EPNS Research meeting and do an excellent job organising the EPNS Journal Club webinars which take place on the 4th Wednesday in alternate months to the EPNS Case Discussion Webinars. For more information <https://www.epns.info/epns-journal-club/> and details are shared in the YEPNS update in this annual report.

I wish you all the best and hope to see you in 2024 at the EPNS Research Meeting in Ljubljana!

**Best wishes**

**Barbara Plecko, Chair EPNS Research & Scientific Committee**



## EPNS Education & Training Committee

### The Moodle

In July 2023, we were delighted to roll out the EPNS Moodle, which is a learning platform designed to provide our EPNS members with a 'one stop shop' learning environment where they can find all EPNS educational and scientific resources. It is a new way to access EPNS resources. EPNS members who have paid their current year EPNS membership fee can login to the EPNS website, click on the 'EPNS Moodle' button and see webinar recordings, EPNS Training presentations, etc.



Photo: Dana Craiu  
Chair EPNS Education and Training  
Committee

### EPNS Exam

The EPNS Exam assesses the basic knowledge needed to underpin Paediatric Neurology training. It is as an exam which will benefit Paediatric Neurology trainees/residents who are qualified physicians and have completed at least 2 years training and established registered Paediatric Neurologists who currently practice in the field of Paediatric Neurology and would like an assessment of their continuing knowledge.

Achieving a pass in the EPNS Exam is an excellent personal goal in this area of specialised medicine. Candidates who have passed the EPNS Exam have an additional qualification which may be an advantage when applying for a new role.

Candidates wanting to test their knowledge, including those in countries without a nationally recognised exit exam, will find it very helpful.



On 20 June 2023 the first summative EPNS Exam took place in Prague. There were 100 Multiple choice Kprim and A questions of a high standard. I thank all candidates for their participation, and I extend my congratulations to all those who successful passed the EPNS Exam and have been issued a certificate. All candidates were invited to complete a feedback survey and their comments have been invaluable for our future development of the EPNS Exam. Plans are already making good progress to prepare for the next EPNS Exam taking place on 8 July 2025.



To sit the EPNS Exam, you do not need to be an EPNS member but you must belong to one of the following 2 categories:

- Residents/trainees in Paediatric Neurology with at least 2 years of training, at the time of the EPNS Exam and who are already qualified physicians and. Note: Candidates and their tutor/trainer will need to sign a proforma of confirmation to complete registration.
- Registered as a specialist Paediatric Neurologist and currently working in a major commitment in the field of Paediatric Neurology. Note: Candidates will need to sign a proforma of confirmation to complete registration.

The EPNS Exam covers a broad range of Paediatric Neurology and is based on the [EPNS Learning Objectives](#) and [EPNS Training Guide](#)

### Young EPNS (YEPNS)

With pleasure, I can announce that this committee is now aligned with the YEPNS Clinical and Research Working Group, who organise Case Discussion webinars on the 4<sup>th</sup> Wednesday of every other month at 17:00h CET. More details are shared in the YEPNS update in this annual report.

### EPNS Central Eurasia Workshop 2023



This highly interactive and successful event took place in Almaty, Kazakhstan on 12-14 April 2023 organised locally by Marzan Lepessova and Altynshash Jaxybayeva. The Workshop covered assessment tools in neonates and young children with the course Moderators Leena Haataja and Altynshash Jaxybayeva. The main themes were structured neurodevelopmental assessments, and intervention in early infancy: evidence and integration into clinical practice.



## EPNS Training Course: Riga, Latvia 2023

The EPNS has a 3-year rolling EPNS training programme with an aim to cover most main topics in the EPNS Training Guide over the cycle, promote contact between paediatric neurology trainees and for qualified paediatric neurologists to refresh their knowledge.

Riga, Latvia was the venue for the training courses in 2023 organised locally by Jurgis Strautmanis.



### 24-25 April 2023: Neurometabolics



The Moderators were Barbara Plecko and Michel Willemsen

This course was accredited with 11 European CME credits (ECMEC®s).

### 26-27 April 2023: Epilepsy



The Moderators were Dana Craiu and Lieven Lagae

This course was accredited with 10 European CME credits (ECMEC®s).

With a total of 35 different countries represented, 92 delegates attended the Neurometabolics course, and 93 delegates attended the Epilepsy course. We were delighted to award 30 bursaries for the course and a total of 71 cases were presented by delegates. The feedback received was excellent and thanks are extended to all involved.



Please take a moment to enjoy this short video about the event:

<https://youtu.be/7xBK8HWz1b0>



## EPNS Monthly Webinars

The EPNS FREE 60–90-minute educational webinars on topics of key interest to Child Neurologists on the 2nd Wednesday of each month at 17:00h CET has become a well-established event in the diaries of both EPNS members and non EPNS members. Feedback continues to confirm that they are a useful and appreciated teaching tool. Each webinar is broadcast live on Zoom and available for FREE to anyone who would like to register, and those who attend for the full broadcast receive a certificate of attendance. Fully paid up EPNS members can access a recording of the full session via the EPNS website after the event, together with a list of recommended references from the guest speaker. In addition, each speaker is invited to write a Teaching Review on their topic to align with the new EPNS Training Guide & EPNS Exam within 3 months after the webinar. The Teaching Reviews are accessible for educational purposes to paid up EPNS members via the EPNS website.

Below is the webinar schedule for 2023:

Date	Topic	SPEAKER	Chair
11-Jan-23	Approach to the child with opsoclonus-myoclonus ataxia syndrome	Ming Lim	Kevin Rostasy
08-Feb-23	Status Dystonicus: Identification, Management and Prevention	Jean Pierre Lin	Dewi Bakker
08-Mar-23	Tuberous sclerosis complex – diagnosis and management	Anna Jansen	Dimitrios Zafeiriou
12-Apr-23	Neurological impairment of disorders of purines & pyrimidines	Marie-Cécile Nassogne	Ming Lim
14-Jun-23	Infantile epileptic spasms syndrome early diagnosis and management	Finbar O'Callaghan	Jean-Pierre
28-Jun-23	Rett Syndrome and related disorders	Nadia Bahi-Buisson	Dana Craiu
13-Sep-23	Cerebral venous thrombosis - diagnosis and multidisciplinary management	Manoelle Kossorotoff	Dilek Yalnizoğlu
11-Oct-23	Clinical and investigational approach of a floppy infant	Laurent Servais	Agnese Suppiej
08-Nov-23	A practical approach to the child with abnormal eye movements	Agnese Suppiej	Dewi Bakker
13-Dec-23	Genetic testing: what a Paediatric Neurologist should know about choosing the right test and interpreting the results	Dana Craiu	Kathleen Gorman

For more information <https://www.epns.info/epns-free-monthly-webinars/>



## Child Neurology in Infancy Online Courses

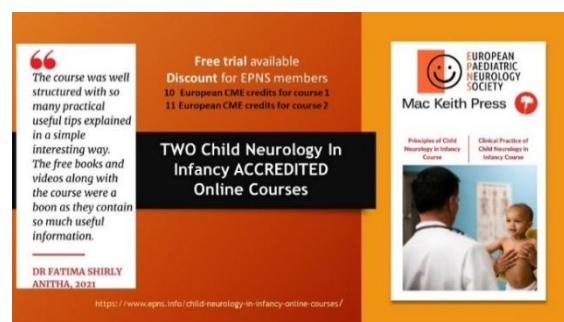
As a result of a collaboration project, the EPNS and Mac Keith Press are offering interactive online learning courses based on the 2nd edition of the Professor Colin Kennedy book *Principles and Practice of Child Neurology in Infancy*.

There are 2 courses:

**Course 1:** Principles of Child Neurology in Infancy.

**Course 2:** Clinical Practice of Child Neurology in Infancy

For more information <https://www.epns.info/child-neurology-in-infancy-online-courses/>



## EPNS Fellowships 2023

The following EPNS Fellowships took place in 2023:



Margherita Bonino  
from Italy to Belgium.



Matthias De Wachter  
from Belgium to Denmark.



Mohammad Kurd  
from Israel to UK.



Ekaterine Kurua  
from Georgia France.



Melis Ozkan  
From Turkey to Germany.



Teresa Painho  
from Portugal to UK



Jacopo Sartorelli  
from Italy to UK



Pinar Yavuz  
from Turkey to UK.

Since 2014 when the scheme started 54 Fellowships have been awarded.

## EPNS Visiting Teacher 2023

The application period for EPNS Visiting Teacher 2023 opened in summer 2022, and with pleasure 2 were awarded as follows:

- **David Neubauer** from Slovenia visited Almaty State Institute of Advanced Medical Education in **Kazakhstan** to share knowledge about new treatment in childhood epilepsy, cognitive impairment in patients with epilepsy and clinical features epilepsy in neurometabolic and neurogenetic diseases.
- **Tally Lerman Sagie** from Israel plans to visit the Carol Davila University of Medicine Bucharest, **Romania** but sadly this has been postponed. The visit will take the shape of a theoretical course and hands-on learning ultrasonography for evaluation of the multiple brain anomalies using a special machine simulator.

## EPNS Training Course: Ferrara, Italy 2024



Ferrara, Italy will be the venue for the training courses in 2024, 2025 and 2026 organised locally by Agnese Suppiej.

The moderators have organised stimulating programmes for the 2024 courses as follows:

**Acute Neurology:** 26 and 27 February 2024

Moderators: Dewi Bakker and Kathleen Gorman

Programme: [CLICK HERE](#)

**Neurophysiological Investigations:** 28 and 29 February 2024

Programme: [CLICK HERE](#)

Moderator: Dana Craiu and Agnese Suppiej

30 bursaries have been awarded and the number of total delegates is limited to 100 to preserve the interactive nature of the EPNS training courses. Invitations to submit case presentations will be sent to all registered delegates.

Learn more here: <https://www.epns.info/epns-training-course-ferrara-italy-2024/>



Ferrara

## 5th EPNS Masterclass 2024



This EPNS biennial event will take place on 19-21 September 2024 at Corpus Christi College, Cambridge, UK (accommodation also in St Catz and Gonville and Caius) and the topic this time is 'Great Expectations

Expectations are growing all the time in our specialty: new diagnostic techniques and groundbreaking treatments appear incredible one day; but by the next have become the "new normal" that everyone expects of us. New possibilities bring new responsibilities: to make diagnoses as rapidly as possible to ensure best possible outcome; to offer every treatment possible, as close to home as possible. Who will pay for these new capabilities? Or give us the extra time we now need to deliver them? How can we carry on doing more and more? And there are still so many situations we can't help — catastrophic brain injury, many remaining neurogenetic disorders. Families' expectations have been raised by the good news stories: 'why can't my child have that treatment I read about online?' "I don't believe you when you say there's nothing that can be done". We may believe their expectations are unrealistic but how can we be sure? What are the limits of recovery in the brain? When should we strive? And when should we ask parents to accept that whilst care is very possible, cure isn't?

As well as the world class clinical and neuroscience faculty you expect from the EPNS we will have parents, ethicists, philosophers and researchers from disciplines you don't ordinarily meet speaking.

The EPNS Cambridge Masterclass has established itself as something special...

<https://www.epns.info/epns-cambridge-master-class-2024/>



## EPNS Fellowships 2024

The application period for EPNS Fellowship 2024 opened in summer 2023. Congratulations to the following who have been awarded an EPNS Fellowship to take place in 2024:



Johanna Wagner  
**AICARDI**  
From Germany to UK.



Ayberk Selek  
From Turkey to Germany



Dekel Avital  
From Israel to UK.



Luca Bergonzini  
From Italy to UK



Alba Gabaldon Albero  
From Spain to UK



Tinatin Nadiradze  
From Georgia to UK



Rosa Pugliano  
From Italy to Belgium



Maria Elisa Morelli  
From Italy to Spain

## EPNS Visiting Teacher 2024

The application period for EPNS Visiting Teacher 2024 opened in summer 2023, and with pleasure 2 have been awarded as follows:

- Kevin Rostasy, Germany, will visit Astana Medical University in Kazakhstan**  
 Approach to a child with a suspected autoinflammatory disease in the context of the extensive differential diagnosis. Further, the spectrum of white matter diseases including NMOSD, MOGAD, MS and other rare entities will be discussed through a series of case presentations given by the participants and formal teaching.
- Dana Craiu, Romania, will visit Kyrgyzstan.**  
 Epilepsy disorders: the lectures will be interactive and based on case-examples; topics covered will be Epilepsy diagnosis; Epilepsy classification including 2022 syndromes classification. Treatment choice based on current guidelines, including epilepsy surgery and ketogenic diet. Treatment discontinuation and epilepsy in females will be other subjects. Case discussion and differential diagnosis will use EEG and video-EEG investigation methods, MRI and PET.

I wish you all the best and hope to welcome you to an EPNS educational event in 2024!

**Best wishes**

**Dana Craiu, Chair EPNS Education and Training Committee**



## EPNS Membership, PR, and Website Report

The Committee are delighted to report that in 2023 we continue to welcome new members to the Society.

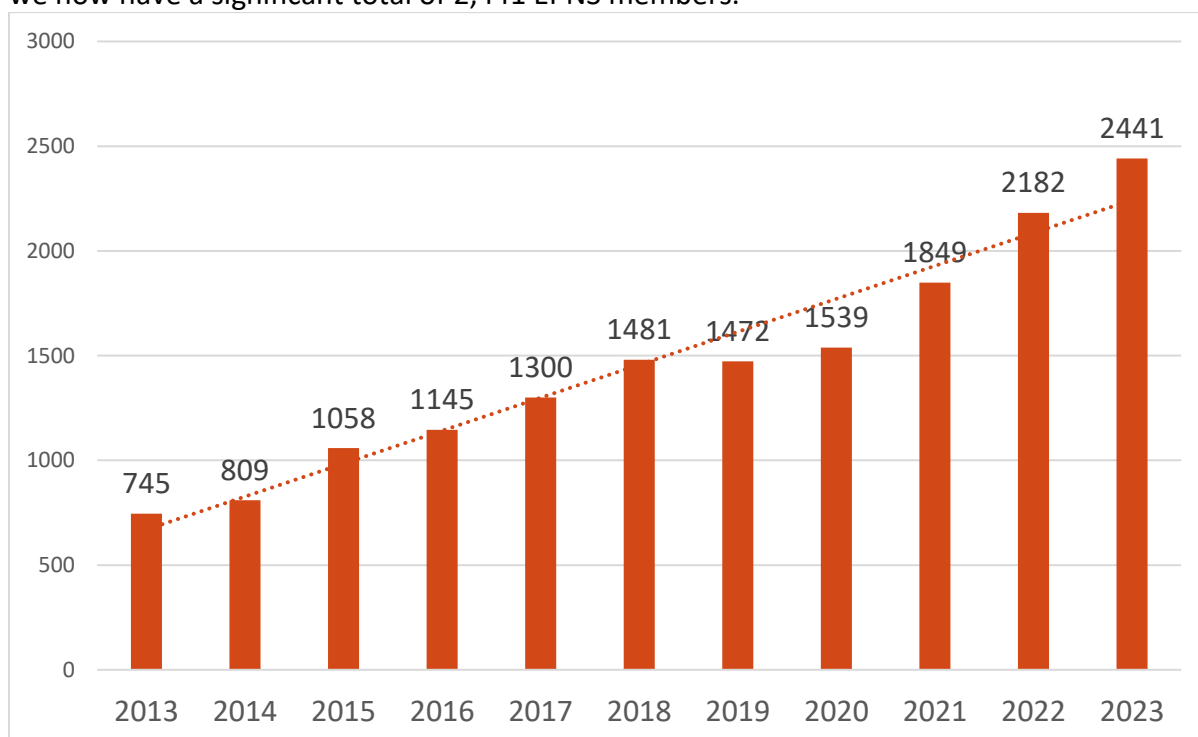
By expanding our membership base, more colleagues in our field can engage in EPNS education, research and networking opportunities thus strengthen the Society's voice in advocating for paediatric neurology at the highest level.

Children and young people with neurological disorders are at the centre of everything we do, and it is our members who are at the heart of the EPNS.



Photo: Jean-Pierre Lin  
 Chair EPNS Membership,  
 PR & Website Committee

The number of EPNS members over the last year has increased, and we now have a significant total of 2,441 EPNS members.



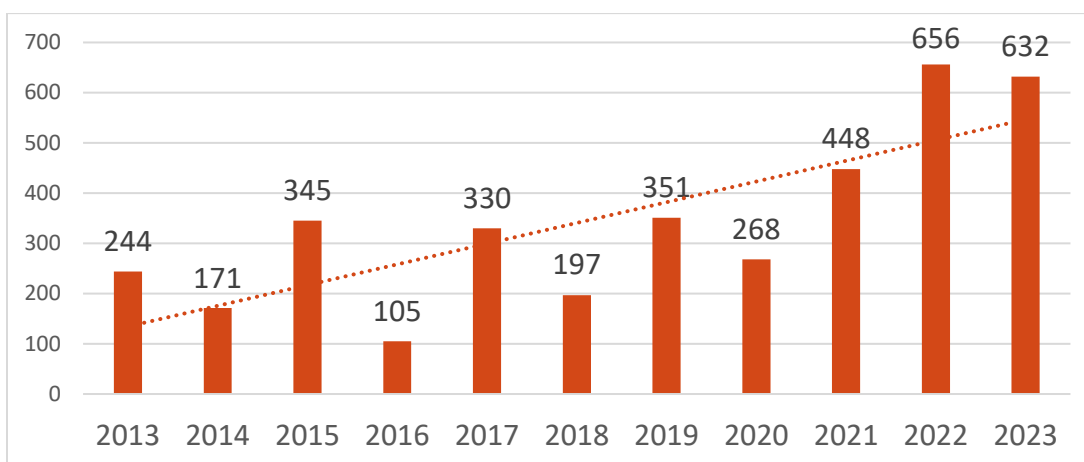
It should be noted that any EPNS members who do not pay their EPNS membership fee over a 2-year period are removed from the EPNS membership database but will continue to receive EPNS newsletters.

The current membership would in fact exceed 2,500 if fluctuations in membership fee payment-default were reduced.



## EPNS new members in 2023

It has been a pleasure to welcome 632 new members.



## Ratifying new members

All new members are welcomed to the EPNS as an Associate Member. Ordinary membership is ratified by the Board and approved by a vote at the general meeting of members. The EPNS Board ratified qualifying members who have joined since the last meeting on 2 May 2022 and on 24 June 2023 were approved by the general assembly.

## EPNS New Membership Categories

We have introduced three new membership categories for colleagues who are an indispensable part of modern child neurology practice. All members in these categories are eligible to pay the same discounted EPNS membership fee already offered to EPNS trainee paediatricians and trainee paediatric neurologists:

- **AHPN** = Allied Health professionals and Nurses with an interest in Paediatric Neurology, e.g., Specialist Nurse Practitioners, Physiotherapists, Occupational Therapists, Speech and Language therapists, Psychologists/Neuropsychologists, Dieticians, Radiographers, etc.
- **NSCS** = Neuroscientists and other Clinical Specialists with an interest in Paediatric Neurology. This is a broad group ranging from bench scientists to specialized technically trained individuals encompassing: Neurogenetics, Neurochemistry, Neurophysiology, neurodevelopmental biology, Neuroepidemiology, health economists, data modelling (machine learning) specialists, etc.
- **PhD Student** = full time PhD Students
- **Medical Student** = undergraduate students interested in Paediatric Neurology

## EPNS membership fees 2024

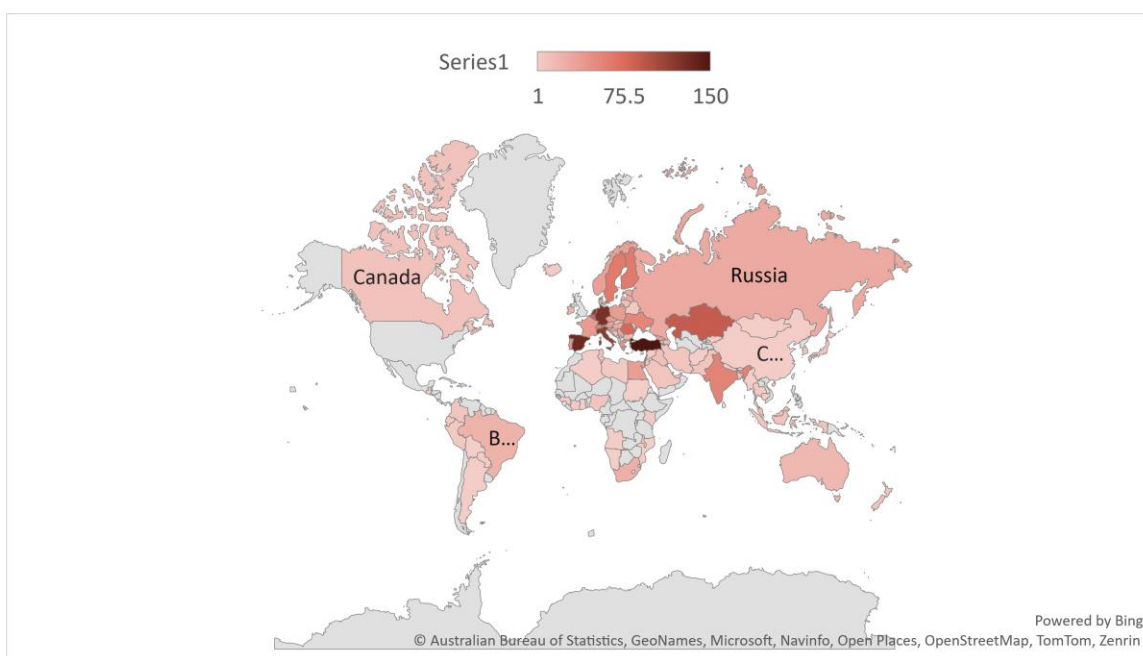
EPNS membership fees are payable each year and cover the period 1 January until 31 December. See the end of this report for more information, where I am pleased to report that EPNS membership fees have remained the same in 2024 as they were in 2023.



## Geographic Distribution of EPNS Members:

It is heart-warming to consider the wide geographical distribution of our EPNS membership which gives the EPNS a global strength and resilience:

Continent	EPNS members	% total membership
Europe	2047	83.9%
Asia	193	7.9%
Africa	102	4.2%
N America	32	1.3%
S America	42	1.7%
Oceania	25	1.0%



Based on population statistics it is possible to calculate the ratio of EPNS members per number of children. In the charts on the next page, the country is ranked according EPNS members per number of children, producing some interesting results! Please note that the EPNS membership numbers are as they were on 1 October 2023 and the source of the other data is [https://www.ejpn-journal.com/article/S1090-3798\(20\)30157-4/pdf](https://www.ejpn-journal.com/article/S1090-3798(20)30157-4/pdf)



**Europe:**  
**Sorted by**  
**no. children/  
no. EPNS members**  
**at 1 October 2023**

Top 50%

Note: end column can be >100%  
because we have members who are  
not Paediatric Neurologists

Country	Total population	No. of Children	No. PNs	Children per PN	EPNS members	Children per EPNS member	% EPNS members/PNs
Estonia	1,329,139	273,155	15	18,210	28	9,756	187%
Slovenia	2,079,772	400,000	9	44,444	39	10,256	433%
Latvia	1,825,476	358,762	48	7,474	26	13,799	54%
Finland	5,565,846	1,000,000	97	10,309	62	16,129	64%
Georgia	3,966,823	750,000	241	3,112	35	21,429	15%
Greece	10,274,549	1,000,000	33	30,303	42	23,810	127%
Austria	9,156,479	800,000	50	16,000	30	26,667	60%
Iceland	347,711	80,000	6	13,333	3	26,667	50%
Belgium	11,736,910	2,285,000	60	38,083	78	29,295	130%
Cyprus	1,233,032	150,000	4	37,500	5	30,000	125%
Netherlands	17,245,556	3,500,000	85	41,176	115	30,435	135%
Switzerland	8,839,497	1,663,752	77	21,607	54	30,810	70%
Norway	5,545,070	1,100,000	60	18,333	32	34,375	53%
Sweden	10,283,190	2,200,000	180	12,222	64	34,375	36%
Croatia	4,105,267	900,000	20	45,000	24	37,500	120%
Serbia	8,634,703	1,300,000	42	30,952	31	41,935	74%
Denmark	5,851,759	1,160,384	80	14,505	26	44,630	33%
Portugal	10,109,965	2,000,000	59	33,898	41	48,780	69%
Israel	9,051,202	2,800,000	180	15,556	57	49,123	32%
Ireland	5,098,955	900,000	7	128,571	18	50,000	257%
Spain	46,807,636	6,500,000	521	12,476	129	50,388	25%
Armenia	2,979,412	800,000	43	18,605	15	53,333	35%



**Europe:**  
**Sorted by**  
**no. children/  
no. EPNS members**  
**at 1 October 2023**

lower 50%

Note: end column can be >100%  
because we have members who are  
not Paediatric Neurologists

Country	Total population	No. of Children	No. PNs	Children per PN	EPNS members	Children per EPNS member	% EPNS members/PNs
Czech republic	10,766,817	2,000,000	200	10,000	37	54,054	19%
Lithuania	2,611,627	541,300	80	6,766	10	54,130	13%
Romania	18,863,449	4,500,000	120	37,500	77	58,442	64%
Bulgaria	6,795,927	1,100,000	33	33,333	17	64,706	52%
Hungary	9,588,780	1,800,000	90	20,000	27	66,667	30%
Slovakia	5,467,361	900,000	39	23,077	13	69,231	33%
Kazakhstan	19,433,024	7,000,000	250	28,000	88	79,545	35%
United Kingdom	68,926,465	13,000,000	75	173,333	160	81,250	213%
Italy	60,202,387	9,000,000	450	20,000	110	81,818	24%
Albania	2,868,627	979,110	15	65,274	9	108,790	60%
Bosnia Herzegovina	3,221,304	700,000	8	87,500	6	116,667	75%
Germany	84,566,144	15,000,000	780	19,231	122	122,951	16%
Ukraine	42,967,484	7,833,460	700	11,191	53	147,801	8%
Turkey	86,990,793	24,000,000	240	100,000	139	172,662	58%
Poland	37,725,646	7,400,000	441	16,780	36	205,556	8%
Azerbaijan	10,406,166	2,800,000	265	10,566	13	215,385	5%
Moldova	4,006,607	707,600	98	7,220	3	235,867	3%
France	65,695,177	14,000,000	250	56,000	38	368,421	15%
Kyrgyzstan	6,838,557	2,165,000	65	33,308	4	541,250	6%
Uzbekistan	34,886,939	12,000,000	515	23,301	15	800,000	3%
Russia	146,117,279	29,000,000	3400	8,529	28	1,035,714	1%

Perhaps some EPNS members would like to delve more deeply into this data to determine if there is a true correlation between numbers of EPNS members and childhood neurological disorder outcomes?

## EPNS Website

The EPNS website <https://www.epns.info/> continues to evolve and there have been enhancements to the EPNS database as part of our ongoing drive to continuously improve and keep up to date with the latest security and technology. Our new EPNS webmaster, Ignacio Malaga Diéguez, will be developing additional EPNS Website functionality to enable easier and more practical interaction between membership individuals and groups.



The EPNS website is very much a shared resource between all the EPNS Committees and their respective activities but can also support National and International needs for communication and project-sharing. Ideas and suggestions for website development should be shared with Ignacio Malaga Dieguez.

## Young EPNS (YEPNS)

With pleasure, I can announce that this committee is now aligned with the YEPNS social media and Networking Working Group, and we look forward to engaging more with this enthusiastic group in the future. More details are shared in the YEPNS update later.

Thank you to all our EPNS Members for contributing to making 2023 such a success, wishing all our EPNS members all the very best for 2024.

## Best wishes

**Jean-Pierre, Chair EPNS Membership & Public Relations Committee**

## EPNS Advocacy & Collaboration Report

This committee formed about 2 years ago and during this time we have been focused on raising the voice of Child Neurology and promoting the aims of the EPNS. Our goal is to advocate at the highest level for the life-course approach to brain health from antenatal influences on brain development, through to childhood, adolescence and onto later life. Plus, we continue to develop fruitful collaborations with related societies. The committee continues to reflect on our collaborations to ensure they are beneficial to the EPNS goals.



Photo: Anna Jansen  
 Chair EPNS Advocacy &  
 Collaboration Committee

## Intersectoral Global Action Plan on epilepsy and other neurological disorders (IGAP)



Whilst this committee has many activities, the IGAP is our biggest focus. The World Health Organisation's (WHO) IGAP sets out the actions needed to improve access to care and treatment for people living with neurological disorders through a comprehensive, coordinated response across sectors. In May 2022, Member

States adopted the IGAP 2022-2031, which aims to improve access to treatment and care and quality of life of people with neurological disorders, their carers and families as well as promote brain health across the life-course. It includes actions to be undertaken by all stakeholders to attain the global targets.

The 5 strategic objectives of the global action plan by 2031 are:

1. Raise policy prioritisation and strengthen governance.
2. Provide effective, timely and responsive diagnosis, treatment, and care.
3. Implement strategies for promotion and prevention.
4. Foster research and innovation and strengthen information systems.
5. Strengthen the public health approach to epilepsy.

The EPNS has identified it is our duty to support, advocate and ensure the IGAP is implemented across Europe with specific reference to paediatric neurology and the EPNS Board are working to embed the objectives into all EPNS committees so that they become part of our day-to-day work. In the coming months, the EPNS will form an action plan.

## EPNS Representatives

The EPNS has appointed EPNS Representatives in key organisations and this year has been a busy time. I thank all EPNS representatives for their hard work and dedication.



## Young EPNS (YEPNS)

With pleasure, I can announce that this committee is now aligned with the YEPNS Climate change & Environmental Awareness Working Group, with their primary aim to bring sustainability and the climate issue to Society's priorities. More details are shared in the YEPNS update in this annual report.

## European Medicines Agency (EMA)

The EMA fosters interaction with healthcare professionals, including doctors, pharmacists and nurses who are independent experts in clinical practice, to incorporate the real-world experience of the full spectrum of healthcare into drug development, benefit/risk evaluation and monitoring.

This year the EPNS became an EMA stakeholder to ensure Child Neurology is represented in the evaluation and supervision of medicines.

We will be nominating experts in key paediatric neurology fields to be EMA points of contact.



EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH

## European Brain Council (EBC)

The EPNS has been a full member of the EBC since 2021. The EBC is non-profit network of key players in the "Brain Area" which consists of Scientific societies, patient organisations, professional societies, and industry partners.

Sameer Zuberi is the EPNS legal representative.

The EBC is a powerful supporter for prevention, early diagnosis and treatment of brain diseases and research of the brain as a priority for Society. Through this network, the EPNS is advocating at an EU level for the life-course approach to brain health from antenatal influences on brain development, through to childhood, adolescence and onto later life.





## Education, Promotion, Networking, Science for Paediatric Neurology

The EBC organised a Brain Awareness week starting on 16 March 2023 which I attended and reflected on the importance of focusing on brain capital and our future generations.



We were pleased to welcome the EBC to the recent EPNS Congress in Prague, where they had an exhibition desk, and the EPNS have been involved in many of the EBC activities including the animal research project, Rethinking projects, Value of Treatment discussions and the EBC strategic workshop in September 2023.

The EBC organised the Brain Innovation Days (BIDs) which took place on 26-27 October 2023 and centred around building resilience and better brain health for future generations and increasing our brains' readiness to adapt to an ever-changing environment. Sameer Zuberi was a member of the Steering Committee for the BIDs programme, and we were delighted that he was able to chair a session entitled 'In Discussion With: Innovative Gene-Related Therapies' session with insights from amongst others, EPNS Board member, Francesco Muntoni. Also,

during the event, the Young EPNS (YEPNS) presented a Poster '*Climate change and Environmental awareness: a European working group to study the environmental impact and promote sustainability in Child Neurology*'. Tessa Wassenberg and Maria Gogou represented the YEPNS at the event.

## Coordination and Support Action (CSA) Brain Health

The European Commission is launching a European Partnership on Brain Health in 2025/2026 to further coordinate and structure the area of brain health research in Europe. To prepare for this, the CSA has been kicked off, with the EBC involved as one of the several partners. The EPNS looks forward to contributing to this group in developing a European Brain Health landscape, identifying priorities, advocating for brain health, and creating a collaborative framework by speaking with one voice.

## 78th United Nations General Assembly

The EBC invited Kevin Rostasy, EPNS President, to attend the Brain Health & Research Day on 18 September 2023 in New York. This was an excellent opportunity where policymakers, researchers, clinicians, industry leaders, patient representatives & non-profits met from all over the world with the purpose of putting Brain Health higher up on the UN agenda.



## European Academy of Neurology (EAN)



The EAN is a Society focusing on Adult Neurology in Europe, working closely with the EPNS. The two societies have a Memorandum of Understanding to collaborate in education & research. The EPNS is pleased to have representatives on nineteen EAN scientific panels, which have a significance for child neurology. The Presidents of the 2 societies meet regularly with other board representatives and the collaboration is developing stronger with an emphasis on especially working together in the field of brain health, guidelines and the process of transition. Building on this collaboration, a joint EPNS/EAN webinar on headache treatment is planned in 2024 and the EPNS looks forward to being part of the next EAN Congress in Helsinki, 2024. You will read in Dana Craiu's Guideline Committee update in this report about the recently formed EPNS/EAN Taskforce on Transition which is an important step in this area.

## Brain Health Mission



This year the EPNS joined the Brain Health Mission (BHM) as a strategic partner. The BHM is an inclusive advocacy initiative, to get various stakeholders on board to create general awareness for the importance of Brain Health – from doctors to caregivers as well as patients, governments, industry etc.

I attended the first Brain Health Summit on 16 November 2023 in Brussels.

## European Reference Networks: ERNs

ERNs are virtual networks involving healthcare providers across Europe focusing on complex or rare diseases and conditions. The EPNS are actively involved in the following 10 networks and has develop new Memorandum of Understanding with several (indicated by \*).



European  
Reference  
Networks

- EpiCARE: European Reference Network on epilepsy \*
- ERN NMD: European Reference Network on neuromuscular diseases \*
- ERN-RND: European Reference Network on neurological diseases
- ERN ITHACA on congenital malformations and rare intellectual disability \*
- ERN-rita care of patients with Rare Immunological Disorders \*
- ERNICA: European Reference Network on inherited and congenital anomalies
- ERN EYE: European Reference Network on eye diseases
- MetabERN: European Reference Network on hereditary metabolic disorders
- Endo-ERN European Reference Network on endocrine conditions
- ERN Paedcan: European Reference Network on Paediatric Oncology

## European Academy of Childhood Disability (EACD)

We are delighted to further cement our relationship with the EPNS with the recently signed Memorandum of Understanding and EPNS will be participating in a joint session at the next EACD Congress on 29 May 2024 in Bruges.





## European Scientific Societies

The EPNS has represented within the following societies in our mutual goal to improve the lives of children:

- European Academy of Paediatric Societies (EAPS)
- European Society for Child & Adolescent Psychiatry (ESCAP)
- Société Européenne de Neurologie Pédiatrique (SENP)

## European Patient Groups

The EPNS also has representation in two European Patient groups: European Federation of Neurological Associations (EFNA) and EURORDIS and the EPNS will continue to develop these relationships:

## Committee of National Advisors: CNA

With one representative from almost all European national paediatric neurology associations, this committee report continues to be a valuable network in spreading the word about the activities of the EPNS and assisting in important projects. I pass on my thanks to all members of the C N A.

## OneNeurology



The EPNS is a partner of OneNeurology which is an initiative aiming to unite and strengthen neurology-related groups to stimulate collaborative advocacy, action and accountability for the prevention,



treatment, and management of neurological disorders worldwide.

OneNeurology was an instrumental player in implementing and communicating the IGAP and is now focusing on implementation through the member states. We are delighted to announce that Coriene Catsman-Berrevoets, EPNS honorary member, was recently elected as vice Chair of OneNeurology for 2 years and will be a great asset in advocating for child neurology. The paper 'Global synergistic actions to improve brain health for human development' was recently published in Nature Neurology Review featuring EPNS members as co-authors.

## International League Against Epilepsy (ILAE)



The ILAE is the world's leading association of health care professionals and scientists working toward a world where no person's life is limited by epilepsy. The EPNS is looking forward to working more closely with the ILAE and currently a Memorandum of Understanding is being established.



## International Presidents



This special group meets virtually every 6 months with the aim to collaborate and avoid duplicating activities. One of the current initiatives focuses on working together to ensure steps are being taken to develop a Global Regional Initiative Programme (GRIP) which aims to upskill a region in the space of child neurology.

## Conclusion

As you can see, the foundations of this committee are becoming firmly cemented into the fabric of the EPNS. We are looking forward to continuing to represent our patients and their carers, developing bright collaborations, and advocating for paediatric neurology to help our community provide better care for our patients.

I wish all our EPNS members the very best.

## Best wishes

**Anna Jansen, Chair EPNS Advocacy and Collaboration Committee**

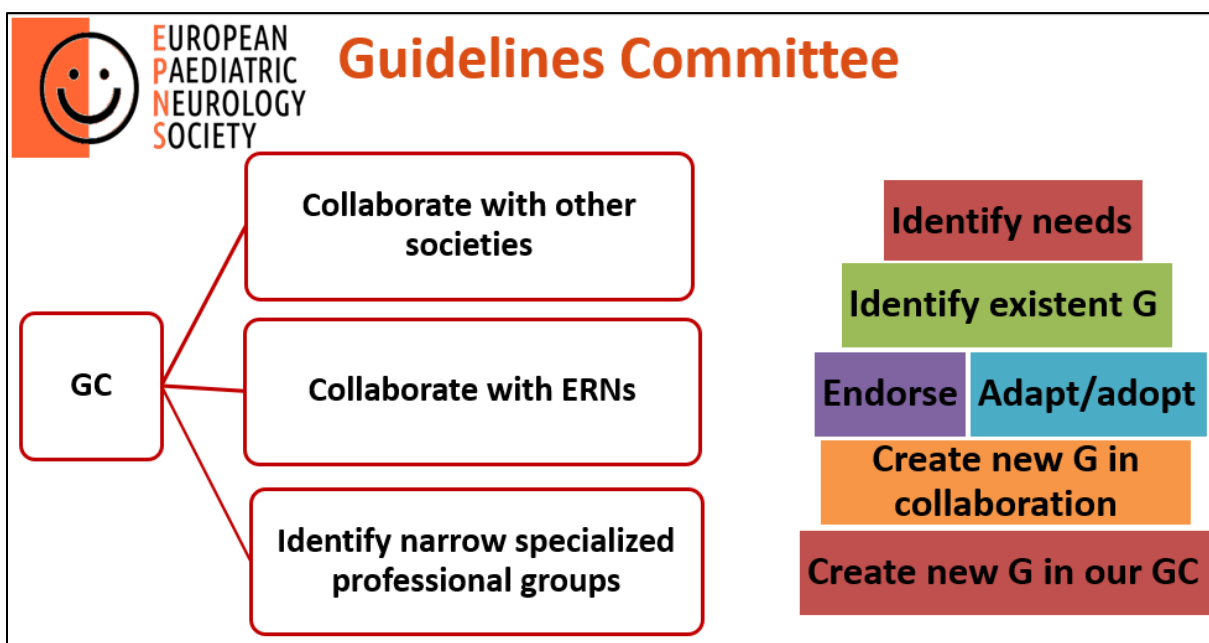
## EPNS Guidelines Committee (GC)

### Scope

The EPNS Guidelines committee was created for promoting high-quality and homogenous patients care (diagnosis, treatment) based on existent evidence all over Europe. The Committee is formed of eminent professors, members of the EPNS Board and numerous invited specialists, non-board members (for specific tasks), CNA and the YEPNS members of the Guidelines Group. There is an important collaboration with the A&C committee facilitating cooperation with the ERNs and different professional societies (EAN, ILAE) or narrow specialized professional groups serving in the area of neurological disorders, based on MoUs (Memorandum of Understanding) for guidelines production. The EPNS President and the EPNS Scientific Committee approve the Guidelines Committee activities.



Photo: Dana Craiu  
Chair EPNS Guidelines Committee



### Young EPNS (YEPNS)

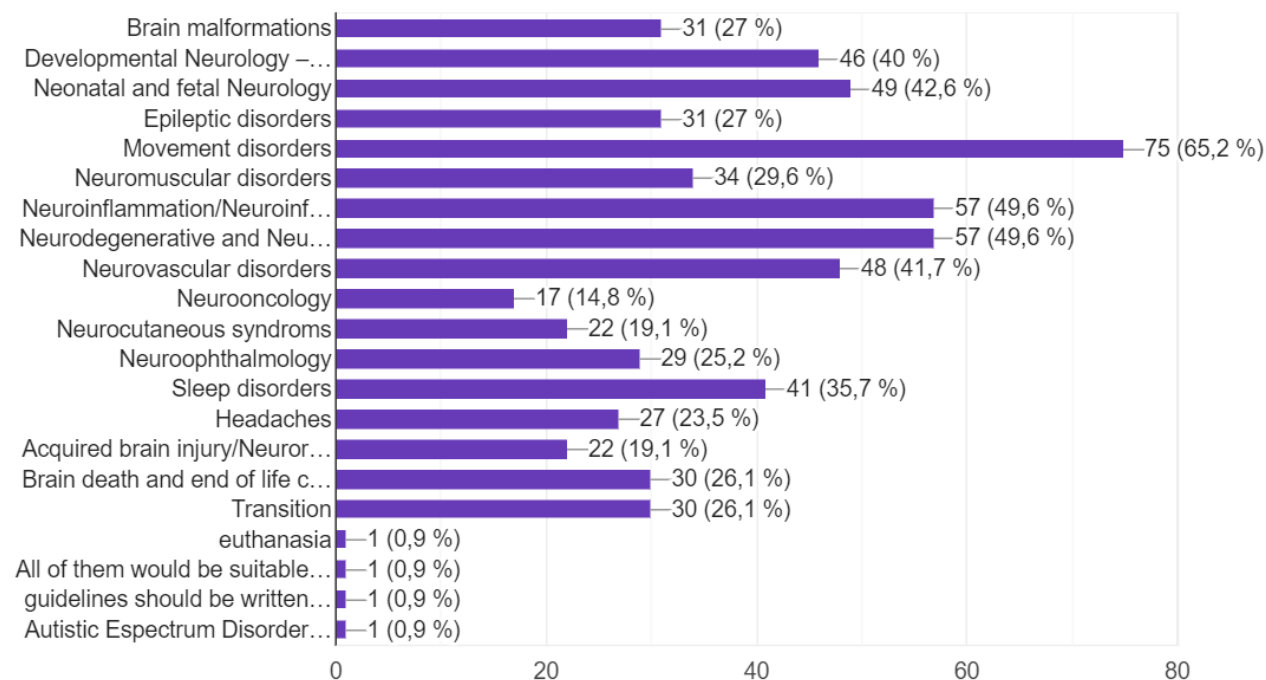
With pleasure, I can announce that this committee is now aligned with the YEPNS Guidelines Working Group, and members of this Group have been a tremendous support. More details are shared in the YEPNS update in this annual report.

### Prioritisation

Following the distribution of the questionnaire created by the GC of the EPNS and YEPNS, Marietta Papadopoulou, the current YEPNS president identified the topics for which practice protocols and guidelines are necessary with priority.

Please indicate one or more PN areas that that Guidelines are most lacking:

115 răspunsuri



## EpiCARE – ILAE-EAN-EPNS guidelines

EPNS is currently a partner in the process of guidelines production initiated by EpiCARE in association with other 2 professional societies (EAN, ILAE): Infantile spasms, Dravet Syndrome, Lennox-Gastaut Syndrome. EPNS will also participate in the Epilepsy surgery and Status epilepticus Guidelines. The Guidelines will be published in the EJPN.



## The restless Legs Syndrome guideline

EPNS is a partner of the EAN in production of the European Guidelines on the Management of Restless Legs Syndrome in cooperation with EURLSSG, MDS, EPNS & ESRs. EPNS is represented by Professor Oliviero Bruni in this working group.

## EPNS and Dystonia project

The Italian group headed by Franca Benini launched the Dystonia in Paediatric Palliative care. Jean Pierre Lin represents EPNS as a partner in scoping Delphi project in Dystonia in children.

### **Adoption of the ILAE neonatal seizures treatment protocol**

Kathleen Gorman and a group of non-EPNS Board members applied the Adoption protocol for rare disorders as a standard protocol of endorsement of the ILAE neonatal seizures treatment protocol. The process is going to be finalized January 2024 and the protocol displayed on the EPNS website.

### **Project on Transition in Europe**

I am delighted to report that in collaboration with the European Academy of Neurology (EAN), a new Task Force has been formed with 4 members of the EPNS Board and 4 members of the EAN. The first meeting will take place in January 2024, and I look forward to progressing further.

### **DMD Delphi initiative**

This group, headed by Rosaline Quinlivan, Diana Castro, and Thomas Sejersen regarding the development of a new global Delphi initiative aiming to establish consensus among global experts in DMD on best practice for transitioning patients from paediatric to adult healthcare services will make a written partnership with EPNS, as co-author of the final document; Thomas Sejersen will represent EPNS; the final document will be published in the EJPN.

### **Website**

A subgroup of the GC discussed and decided the pathway of guidelines production and responsible persons for decision making. The information will be soon displayed on the EPNS website.

I am looking forward to keeping EPNS members informed about this important work. We are currently working to identify guidelines with paediatric neurology overlap and are interested in being an active partner in the ERNs guidelines development groups for the guidelines with neurological involvement.

### **Best wishes**

**Dana Craiu, Chair EPNS Guidelines Committee**

## Young EPNS (YEPNS)

I am happy to submit this report at the end of my first year as Chair of the Young EPNS (YEPNS) YEPNS Committee! I would like to thank the former Chair (Jasna Orazem Mrak), all the former and current YEPNS Committee members and the EPNS for setting the ground for and supporting this community that has just celebrated its 3<sup>rd</sup> anniversary!

The YEPNS has continued to grow in 2023 and it is my honor to represent the young section and raise the voice of the young section of this society. YEPNS members have very actively participated in several EPNS exciting projects and a new free YEPNS subscription was set during the EPNS Congress in Prague that will allow more young EPNS members to join the YEPNS and participate on the ongoing and future projects! The electronic form is available on the YEPNS section of the EPNS webpage (<https://www.epns.info/young-epns-yepns/>). This webpage has been further modified including the new Committee members, the goals of YEPNS and a description of its structure.

YEPNS has kept the same structure renaming some of the Working Groups in order to better reflect the current activities with the addition of a new working group on Climate Change and Sustainability, a topic that is of high priority in the Agenda of YEPNS and EPNS. Here is a summary of the main activities of each working group for the past year! Each working group Coordinator has recently been linked to and will be working together with the Chair of the relevant EPNS Committee to facilitate the participation of YEPNS in the conception and development of common projects!

**The Research & Career working group (WG) was coordinated by Jelte Helfferich.** Their primary project - Journal Club webinars successfully presented every other month, planned together with EPNS's Science & Research Committee. The Research and Career WG is also implicated in the development of the EPNS's Exam and Curriculum working group, coordinated by EPNS's Education & Training Committee and in other research activities, as the next EPNS Research Meeting 2024 that will be held in Ljubljana. YEPNS Podcast, initially resuming the content of the Journal Clubs and eventually on different topics too, is the next big project that will be held by this working group. Additionally, ideas on projects to support potential YEPNS/EPNS collaborative research projects are in discussion.

**The Education & Clinic working group was coordinated by Karina Kersbergen.** Webinars in form of "Case Discussions" were prepared, organized, and presented by this working group every other month. Interesting Cases from different fields of Pediatric Neurology were presented by trainees or early-career Pediatric Neurologists with the support and participation of several prominent Senior Mentors. This WG has also organized the successful YEPNS "Guess the syndrome" session during the 15<sup>th</sup> EPNS Congress in Prague. Initial discussions have also been launched in collaboration with the EPNS Education and Training Committee regarding an EPNS mentor-mentee project.



Photo: Marietta Papadopoulou  
Chair Young EPNS (YEPNS)



**The Social Media & Networking working group was coordinated by Roberto Previtali.** Members of this working group were in charge of managing YEPNS's Facebook account (YEPNS), Instagram account (young\_EPNS) and email account ([yepns@epns.info](mailto:yepns@epns.info)) with constantly increasing followers in both accounts. There are regular weekly posts advertising all EPNS/YEPNS activities, when possible in an interactive way (i.e. quizzes regarding the topic of Journal Clubs or Case discussions). Marietta and Ainara Salazar have represented YEPNS in the International collaboration of Young Representatives of World's Paediatric Neurology Societies meetings every three months. Further meetings with young representatives of other neurological societies (ILAE, EAN, Ithaca) took place with plan to formalize mutual collaboration in the future and a common YEPNS/YES session is discussed for the next European Epilepsy Congress.

**The Guidelines & Good Clinical Practice working group was coordinated by Lena Luise Becker.** Several members of this WG were actively involved with EPNS transition guidelines project last year and discussions on how to further evolve this project are ongoing. Several YEPNS members were invited to participate in the ongoing guidelines projects of ILAE/EpiCARE/EAN and recently EPNS joint guidelines. There was also participation in the Appraisal of existing guidelines in order for them to be endorsed by EPNS. An educational file repository along training activities regarding the process of guidelines formation.

**The Climate change and Sustainability working group was created and coordinated by Thomas Foiadelli.** The aim of this group is to raise awareness regarding the impact of climate change in pediatric neurology and to reduce the environmental footprint of YEPNS/EPNS promoting positive actions and collaborations. The members of the working group have already met with Intercongress, the EPNS president and a representative of the organizing committee of the next EPNS Congress in order to discuss ideas for a “green” Congress. The EPNS Advocacy Committee has supported the participation of this working group in the Brain Innovation Days meeting where Tessa Wassenberg has presented a poster on the topic.

Last but not least, **our favorite YEPNS time of the year was the 15<sup>th</sup> EPNS Congress in Prague.** Many YEPNS members have participated in the Congress and submitted their original work for presentation, while also supporting the organization by reviewing submitted abstracts and successfully chairing several poster and parallel sessions. A YEPNS Committee meeting was formally held during the Congress along with many informal discussions and meetings during coffee breaks. The YEPNS “Guess the syndrome” session was presented and coordinated by Thomas, Karina and Marietta with the kind mentoring of Drs Lim and Lin. A very successfully sold-out YEPNS night took place during the congress thanks to the support of the EPNS and Pavel Krsek and the local organizing Committee.







YEPNS Committee has worked intensively in 2023 to promote YEPNS on a national and international level and to continue all the ongoing YEPNS projects! We were happy to see the interest of new members to participate in the activities of the YEPNS with currently more than 80 new YEPNS subscriptions! In 2023, we will address invitations to all new members for joining the meetings of the Working groups and we are optimistic that our community will grow further! We are looking forward to the breath of fresh air in the already very exciting YEPNS projects and to all the new ideas and projects to come! YEPNS

Warm Season's Greetings!

**Kind regards,**  
**Marietta Papadopoulou**  
**Chair Young EPNS**



## Committee National Advisers (C N A)

The Committee of National Advisers is constituted of advisers selected by the national paediatric neurology societies and associations from European countries according to the World Health Organization (WHO) European Region definition. Normally each country is represented by one member. Currently 44 countries are represented in the CNA along with an observer from the European Academy of Neurology (EAN).



Photo: Dilek Yalnizoglu  
Chair C N A

The CNA is a forum for mutual information, discussion and debate on matters relevant to pediatric neurology. The CNA has an executive group consisting of its chairperson, secretary and 3 elected members. The CNA is independent of the EPNS but is intended to work in close relation with it. While the CNA is constituted of advisers selected by the national societies, the EPNS is a society of individual members. The CNA is represented on the board of the EPNS and in its Education and Training committee by its chairperson and elected members. The EPNS is represented in the CNA by its president and other relevant persons as full members of the CNA.

Established in 2022, the EPNS Advocacy and Collaboration Committee will be bringing up new opportunities to improve this relation further.

### C N A Meeting

The CNA meets biennially just before the EPNS Congress. The CNA meeting took place on 20 June 2023, before the 15th EPNS Meeting in Prague, Czech Republic, 20-24 June 2023. It has been a marvellous opportunity for the CNA members to meet finally face to face after online and hybrid meetings due to the pandemic situation during previous years.

Following the hybrid CNA meeting in Glasgow in 2022, this years' meeting brought together 30 representatives. It was a wonderful opportunity for the representatives to gather and hear a comprehensive update about the EPNS activities, as well as bring up comments and questions on relevant topics. Following introduction of the participants, Dilek Yalnizoglu, the CNA Chair, presented an introduction on the role of CNA as well as summary of action points from the meeting in 2022. Kevin Rostasy, the EPNS President, emphasized the importance of CNA for the the EPNS in reaching out to the national societies. Thorough updates on EPNS activities were presented by Dana Craiu, the chair of Education & Training Committee and Guidelines Committee, Barbara Plecko, the chair of Scientific & Research Committee, Anna Jansen, the chair of Advocacy and Collaboration Committee, and Jean-Pierre Lin, the chair of Membership, PR & Website Committee. This years' CNA meeting highlight was the first EPNS Exam held on the same day and at the same floor with the CNA meeting. Maja Steinlin, head of the EPNS Exam Organizing Team, gave a detailed presentation covering the references for the exam, including the EPNS syllabus, training guide with webinar/course synchronisation, and provided information on types of questions and replied all comments and questions regarding the exam by the participants. Subsequently, CNA members were invited to include their local network -if they thought

**Education, Promotion, Networking, Science for Paediatric Neurology**

that would be more productive- and continue to support the upcoming EPNS Exams, by the EPNS Exam Organising Team and the CNA chair.

At the end of the meeting time was reserved for CNA members who wished to present their projects and comments on different topics. Ralitza Yordanova from Bulgaria made a presentation on behalf of Ivan Ivanov and colleagues, 'Survey on mass developmental screening', and invited CNA members to participate. On behalf Vesna Brankovic-Sreckovic from Serbia, Dilek Yalnizoglu mentioned the importance of subspeciality training in Europe under paediatric neurology such as epilepsy and neurophysiology, neuromuscular diseases, and such.

**CNA Executive Committee**

The CNA election takes place every 4 years to appoint the Executive Committee positions: Chair, Secretary and 2 Members for 4 years, and each person can serve 2 times in a particular role. The current CNA Executive Committee for the 2022-2026 term consists of 4 positions:

Dilek Yalnizoglu, Turkey, Chair

Anne-Marie Childs, UK, Secretary, EPNS Board Representative (2024-2026)

Agnese Suppiej, Italy, Member, Elected EPNS Board Member

Monica Vasconcelos, Portugal, Member, EPNS Board Representative (2022-2024)

It has been my honour to serve as the CNA Chair. I thank Monica Vasconcelos for her term as the EPNS Board Representative for the last two years, and welcome Anne-Marie Childs, CNA Secretary, as the EPNS Board Representative for the next two years. Again, I would like to emphasize the enormous potential CNA has to contribute to the EPNS, particularly in education and training aspects, and I look forward to continued support of the CNA in educational initiatives of the EPNS.

Best wishes

**Dilek Yalnizoglu, Chair C N A**



## Training Advisory Board (TAB)

In 2002 Paediatric neurology was accepted at the European level as a sub-specialty of Paediatrics and of Neurology. In the process of defining the specialty, a European Paediatric Neurology Training Programme (Syllabus) was compiled and accepted by the European Paediatric Neurology Society (EPNS) and the national societies represented in the Committee of National Advisors (CNA) in Paediatric Neurology as well as the European Union of Medical Specialists (UEMS) sections for Paediatrics and Neurology. The revised Syllabus was again discussed and accepted with entry both from Paediatrics or Neurology by EAP (European Academy of Paediatrics, the Paediatric Division of UEMS) in December 2010. The Syllabus was revised and updated by a CNA working group in 2019, which was accepted by the General Board of EPNS and by the CNA (<https://www.epns.info/education-and-training/european-syllabus/>).



Photo: Dilek Yalnizoglu  
Chair TAB

In order to push the implementation of a high standard of paediatric neurology training, in 2004 the EPNS Board and the CNA agreed to create a Training Advisory Board (TAB) and to develop a training evaluation programme intended to support national societies in developing their training systems. TAB offers the national child neurology societies the opportunity to evaluate their national training system. The aim is a standard of training in accordance with the European Paediatric Neurology Training Programme (Syllabus) in each European country. The assessment is voluntary and initiated by the national paediatric neurology society. So far the training system was evaluated in 13 countries.

The most recent TAB visit was to Ukraine completed by Dana Craiu (Bucharest, Romania) and Coriene Catsman (Rotterdam, the Netherlands) in 2021. The report of this visit was presented at the EPNS board meeting and at the CNA meeting in 2022, then the approved report was published on the EPNS website (<https://www.epns.info/about-epns/tab/>).

I look forward to working with national paediatric neurology societies while EPNS/TAB continues to support and develop national training programmes. Also, I suggest that national societies of the countries who had been visited in the past may consider if they will benefit from an update visit and re-evaluate their progress and accomplishments over time.

Best wishes

**Dilek Yalnizoglu, Chair TAB**



## European Journal of Paediatric Neurology Report (EJPN)

The European Journal of Paediatric Neurology (EJPN) is the official journal of the EPNS and is available to all members in either electronic or print & electronic format. Published 6 times a year by Elsevier Ltd. on behalf of the society it accepts high-quality papers primarily of a clinical research nature on the whole spectrum of paediatric neurological disease, as well as consensus statements and expert guidelines on current. The journal is owned by the society and contributes to the income of the EPNS through royalty payments.

With an Impact Factor of 3.1, the number and quality of submissions remains high, despite the difficulties posed by the pandemic. Three new special issues on current interesting topics are on the way, with many world-leading basic and clinical neuroscientists contributing articles.

In accordance with the educational nature of EPNS, the Editorial team has already started to publish high-quality “Teaching Papers” on specific topics presented in the EPNS monthly Webinars.

Additionally, the Editorial Team together with the EPNS Board awarded for the first time the “EJPN Paper of the Year” award (original paper), which was presented during the Opening Ceremony of the Biennial EPNS Congress in Prague (June 2023) and which is accompanied by a money prize of 1000 Euros and free registration to the Congress and will be awarded every two years during the Opening Ceremony of each future EPNS Congress.


The journal has a distinguished and recently renewed international Editorial Board of specialists who advise on the direction of the journal, special issues, and review papers, superbly moderated by the five Associated Editors, Deborah Sival, Lucia Gerstl, Alexis Arzimanoglou, Anne Jansen and Ming Lim and who are world-renowned experts in their field.



Photo: Dimitrios Zafeiriou  
Editor-in-Chief, European Journal of  
Paediatric Neurology (EJPN)

Best wishes 

**Dimitrios Zafeiriou, MD, PhD**

**Professor of Pediatric Neurology & Developmental Pediatrics **

**Editor-in-Chief, European Journal of Paediatric Neurology**



### A little more information about

## The European Paediatric Neurology Society (EPNS)

***A society for physicians with a research or clinical interest in Paediatric Neurology.***

**Honorary membership** is for persons who the society wishes to honour for outstanding distinction in the field of paediatric neurology.

**Associate membership** is awarded, on application, to all paediatric neurologists and colleagues in related fields and that belong to their national society or association in their field and to any physician, basic scientist or clinical scientist trainees in paediatric neurology who shows an interest in the neurology of infancy, childhood, or adolescence, whether in research or in clinical medical care. There are no geographical restrictions to associate membership. Associate members pay an annual subscription, which includes subscription to the European Journal of Paediatric Neurology, the Journal of the Society.

**Ordinary membership** is for any associate member that is also in practice in Europe (currently taken as the region for which European Office of WHO is responsible). Transition from associate to ordinary membership takes place by the vote of the general assembly at the meeting of The Society. The only difference between associate and ordinary membership is the entitlement of ordinary members to vote for and stand as candidates for election to the Board of the Society.

## EPNS Membership Fees for 2024

EPNS membership fees (also known as subscription fees) are payable each year and cover the period 1 January until 31 December.

Each fully paid up member of the EPNS receives access to the [EJPN](#) as part of their membership (printed and online ,or online only access, depending on the fee paid).

The EPNS Membership Fee paid for the year 2024 depends on several factors:

### 1. Your EPNS Membership Category

For physicians/medical doctors who specialise in Paediatric Neurology or another medical field with an interest in Paediatric Neurology, the EPNS Membership categories are based on the World Bank (WB) income category of the country in which you practice.

Here is the list of World Bank Classification 4 high income nations [World Bank list of high income economies 2024](#)

- **WB4A**= Physicians/medical doctors who specialise in Paediatric Neurology or another medical field with an interest in Paediatric Neurology who practice in Class 4 high income nations on this list NOT highlighted in blue
- **WB4B**= Physicians/medical doctors who specialise in Paediatric Neurology or another medical field with an interest in Paediatric Neurology who practice in Class 4 high income nations on this list HIGHLIGHTED in blue
- **WB123**= Physicians/medical doctors who specialise in Paediatric Neurology or another medical field with an interest in Paediatric Neurology who practice in countries NOT in Class 4 high income nations, i.e., countries NOT on list this.
- **GNP** = Mutual members of the Gesellschaft für Neuropädiatrie (GNP) and the EPNS

The EPNS also has the following categories for colleagues who have an interest in paediatric neurology. These categories are not based on the World Bank classification, they are the same for all nations:

- **Trainee/Resident**= qualified physicians/medical doctors who are in training to in Paediatric Neurology or another field in medicine and have an interest in Paediatric Neurology
- **AHPN** = Allied Health professionals and Nurses with an interest in Paediatric Neurology, e.g., Specialist Nurse Practitioners, Physiotherapists, Occupational Therapists, Speech and Language therapists, Psychologists/Neuropsychologists, Dieticians, Radiographers, etc.
- **NSCS** = Neuroscientists and other Clinical Specialists with an interest in Paediatric Neurology including PhD students. This is a broad group ranging from bench scientists to specialized technically trained individuals encompassing: Neurogenetics, Neurochemistry, Neurophysiology, neurodevelopmental biology, Neuroepidemiology, health economists, data modelling (machine learning) specialists, etc.
- **PhD** = full time PhD Student
- **Med Stud**= Medical undergraduate students with an interest in Paediatric Neurology

## 2. Online only Journal access or printed Journal too

Each fully paid-up member of the EPNS automatically receives access to the [Society Journal](#) as part of their membership. EPNS members can opt to pay a Membership fee with online access to the Journal or they can pay more and also receive a printed copy of the Journal which will be posted to their nominated mailing address.

### EPNS membership fees for 2024.

EPNS Membership Category	2024	2024
(see above)	online only Journal	printed + online Journal
WB4A	150 Euros	210 Euros
WB4B	75 Euros	135 Euros
WB123	35 Euros	95 Euros
GNP	130 Euros	210 Euros
Trainee/Resident	20 Euros	80 Euros
AHPN	20 Euros	80 Euros
NSCS	20 Euros	80 Euros
PhD	20 Euros	80 Euros
Med stud	20 Euros	80 Euros



## Contacting the EPNS



Photo: Sue Hargreaves  
EPNS Executive Manager



Photo: Mel Knowles  
EPNS Operations Manager



Email

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Website

<http://www.epns.info/>



X/Twitter

[Twitter @EPNSnews](https://twitter.com/EPNSnews)



Instagram

[Instagram @epnsnews](https://www.instagram.com/epnsnews)



Facebook

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## Joining the EPNS

### New members are welcome!

If you are not already a member, please think of becoming one. By doing so you join a growing group of like-minded active professionals in our field who are committed to improving standards of care of all children with suspected neurological problems and to collaborating on training, continuing medical education and research. Membership is open to all paediatric neurologists and colleagues in related fields. Membership rates have been substantially reduced for trainees and for colleagues from certain countries after completion of training.

It's easy to join the EPNS! Our new membership application form can be completed online through our website <https://www.epns.info/become-an-epns-member/new-membership-application/>. Once you submit the form, you will receive an email acknowledging receipt. Sue or Mel from our EPNS Administration Team will then get in touch with you shortly afterwards to formally welcome you to the Society.

