

Annual Report 2016



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

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EPNS President's Overview

Welcome to the first annual report of the European Paediatric Neurology Society (EPNS)! This is a great opportunity to consolidate the year's activities and celebrate the successes of our thriving Society.

The EPNS is a growing society which continues to play an important role in and beyond Europe in the field of Paediatric Neurology. As I look back over the past year and all that has been achieved by the EPNS, I've concluded that this has been an exceptional year for both our organisation and our profession. It is such a privilege to be able to acknowledge the hard work of everyone concerned.

The EPNS Board met two times during 2016 to drive forward the EPNS goals to develop Paediatric Neurology, to give training and education to our younger colleagues at the highest level and to start new scientific and vibrant collaborations.

Please read on to see the reports from the Chairs of our EPNS Committees and learn about our activities which have taken place this year, and our plans.

Thank you for your support this year — and in the years to come — as we strive to serve Paediatric Neurology physicians and their patients.

I hope to see you in Lyon for our 12th EPNS Congress taking place 20-24 June 2017!



Best wishes

Professor Lieven Lagae

EPNS President



Invitation to 12th EPNS Congress



We are delighted to inform you that France will be welcoming the prestigious European Paediatric Neurology Society conference at the Cité Internationale of the city of LYON on 20-24 June 2017.

The main theme for the 2017 meeting will be:

Lifelong course of diseases of the child's nervous system.

Indeed, the prognosis and outcome of diseases of the child's nervous system and their transition to adolescence and adulthood represent important challenges for the family, the patient, health care professionals, the pharmaceutical industry and national authorities. Conversely, mothers' neurological disease, such as muscular, metabolic, autoimmune, psychiatric disorders, might have some consequences in foetus and child neurological outcome.

A growing number of neurologists are involved in the follow-up of patients with neurological diseases revealed in childhood or even in infancy or the neonatal period. Tight interactions between neuro-paediatricians and adult neurologists are mandatory for defining optimum lifelong care management strategies.

This prestigious congress will cover, in plenary and parallel sessions, the following major topics: Epilepsy; foetal neurology, neurodevelopmental disorders such as autism and intellectual disability; CNS inflammatory and vascular diseases; Inherited metabolic diseases.

For more information, please visit the congress website: www.epns2017.com/

We look forward to welcoming you to Lyon!

On behalf of the Organising Committee and EPNS Board



EPNS Board Members 2014 - 2018

President	Lieven Lagae, Leuven, Belgium
Secretaries	Nina Barisic, Zagreb, Croatia Finbar O'Callaghan, London, UK
Treasurer	Florian Heinen, Munich, Germany
Chair Research & Scientific Committee	Linda De Meirleir, Brussels, Belgium
Chair Education & Training Committee	Coriene Catsman-Berrevoets, Rotterdam, Netherlands
Chair Finance Committee	Peter Baxter, Sheffield, UK
Chair of the Membership /Public Relations / Website Committee	Sameer Zuberi, Glasgow, UK
Webmaster	Francisco Carratala, Alicante, Spain
Committee of National Advisors (CNA)	Dana Craiu, Bucharest, Romania Alasdair Parker, Cambridge, UK
Members	Banu Anlar, Ankara, Turkey Guenther Bernert, Vienna, Austria Isabelle Desguerre, Paris, France Rob Forsyth, Newcastle, UK Katalin Hollody, Pecs, Hungary Jean-Pierre Lin, London, UK Alla Nechay, Kiev, Ukraine Barbara Plecko, Zurich, Switzerland Raili Riikonen, Kuopio, Finland Thomas Sejersen, Stockholm, Sweden Maja Steinlin, Bern, Switzerland Biayna Sukhudyan, Yerevan, Armenia Michele Willemsen, Nijmegen, Netherlands Dimitrios Zafeirou, Thessaloniki, Greece



EPNS Treasurer & Finance Report

Our Society is in good financial health. We have adequate capital reserves to cover our current liabilities.

Over recent years there has been a regular budgetary surplus, which was not always the case previously. We are therefore developing systems to give the spending committees (Education & Training, Scientific) a 2-3-year budget to help plan their work. We are also encouraging the submission of projects that need initial capital support, if they fulfil the Society's aims.

We continue to monitor and minimise administration costs. We are also considering the possibility of reducing membership fees for some World Bank 4 countries to align these more closely with income. In addition to our euro account in Germany we have been considering a sterling bank account, but this has been delayed by the UK referendum in June. We are aware that some members have encountered difficulties in trying to pay their subscription and are trying to remedy this. If you do find any problems with your payment, please let us know.

Best wishes

Florian Heinen, EPNS Treasurer

Peter Baxter, Chair EPNS Finance Committee



EPNS Research & Scientific Report

The EPNS Research Meeting is held biennially. This year it was held in Essen, Germany 28-29 October.

Local organising committee:

Prof. Dr. Ulrike Schara, University of Essen

Dr. Kevin Rostasy, University of Witten/Herdecke

Prof. Dr. Thomas Lücke University of Bochum

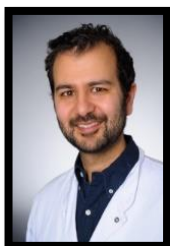
10 bursaries of 500 euro each were awarded.

The 2016 Research meeting started with a plenary session focusing on 2 diverse topics:

- the role of imaging in the field of paediatric neurology
- career aspects of young colleagues.

Also, there were 8 different working groups:

1. Neonatal Neurology, Neurodegeneration & Neuroprotection
2. Neurometabolics
3. Ataxia / Movement Disorders
4. Developmental Neurology and Neuro-rehabilitation
5. Neuromuscular disorders
6. Autoimmune inflammatory diseases
7. Epilepsy
8. Paediatric Stroke



The EPNS Research Prize of 2500 euro per person was awarded to two young neurologists who presented outstanding, innovative ideas in an area of research in Paediatric Neurology. Well done to:
Dr Walid Fazeli from Germany and Dr Ralista Yordanova from Bulgaria

The evaluation forms completed by participants confirmed the meeting was a triumph! There were some very positive comments about the organisation of the meeting with its friendly atmosphere and interesting working groups and programme. The EPNS Scientific and Research Committee will focus on the comments about how we can make the next meeting even better next time. **The EPNS extends its warmest thanks to the Local Organising Committee, the Working Group Chairs and all participants for making the event such a success.**

The 2018 Research Meeting will take place in Alicante.

Continued...



EPNS Research & Scientific Report *continued*

The **EPNS Congress** is held biennially in alternate years to the EPNS Research Meeting.

EPNS Congress 2017 will take place at the Cité Internationale of the city of Lyon, France on 20-24 June 2017. <http://www.epns2017.com/>

The main theme for the 2017 meeting will be:

Lifelong course of diseases of the child's nervous system.



More details about EPNS Congress 2017 can be found on page 3 of this annual report.

EPNS Congress 2019 will take place at the Megaron Athens International Conference Centre in Athens, Greece on 18-21 September 2019.

The main theme for the 2019 meeting will be:

Paediatric Neurology and Rare Diseases: Genetics & Environment, Progression & Transition

Plans are already well underway, and more information will soon be available on the dedicated website:

<http://www.epns2019.org/>



EPNS Congress 2021 the bidding process has started and selected applicants will be invited to present their bid to the EPNS board at EPNS Congress 2017 in Lyon on 20 June 2017. An announcement will be made shortly afterwards.

The EPNS Research & Scientific Committee hope to see you in Lyon in June 2017!

Best wishes

Linda DeMeirleir

Chair EPNS Research & Scientific Committee

EPNS Education & Training Report

In 2016 the E&T committee was responsible for the following teaching opportunities:

- EPNS Training Courses
- EPNS Fellowships
- EPNS visiting teacher



EPNS Teaching Course: Budapest, Hungary

Aim: to cover most main topics in the syllabus over a three-year cycle, promote contact between paediatric neurology trainees AND qualified paediatric neurologists to refresh their knowledge. There were 78 participants from 28 countries. EPNS stimulated participation by granting 30 bursaries.

Local organiser: Professor Katalin Hollódy



8-9 March 2016

Epilepsy and paroxysmal disorders.

Scientific moderator: Professor Katalin Hollódy



10-11 March 2016

Behavioural, psychological & psychiatric aspects of child neurology, including autism and learning difficulties.

Scientific moderator: Dr Peter Baxter



In 2017, topics of the EPNS Budapest teaching courses will be:

- Infantile Metabolic Encephalopathies (IME) and Neonatal Neurology
- Neuromuscular disorders

The Teaching Course will take place Tuesday 4 April – Friday 7 April 2017

Continued...



EPNS Education & Training Report *continued*

EPNS 2nd Caucasian Teaching course in Tbilisi Georgia

Local Organiser: Dr Sophia Bakhtadze and Professor Nana Geladze

There were 60 participants from Georgia, Armenia, Azerbaijan, Uzbekistan, Turkey, Russia, Ukraine, Latvia, and Israel were present.

Scientific organisers on behalf of EPNS:

Richard Newton (Manchester, UK)

Biayna Sukhudyay (Yerevan, Armenia)

Coriene Catsman-Berrevoets (Rotterdam, the Netherlands)



30 September 2016

Neuro-immunology and infection

Faculty: Richard Newton, Rachel Kneen, Ming Lim, Coriene Catsman, Sophia Bakhtadze, Eugen Boltshauser

1 October 2016

Common neurological disorders

Coriene Catsman, Eugen Boltshauser, Biayna Sukhudyay, Hilary Lloyd, Sophia Natriashvili



The aim of EPNS is to organise a 3rd Caucasian course in 2018, making this a biennial tradition.

Continued...



EPNS Education & Training Report continued

EPNS Fellowships

Aim: To create excellence by offering the opportunity for further qualification or experience in an area of paediatric neurology in terms of clinical practice or research. The scheme is targeted at those who are at the early stages of their training in the field of paediatric neurology.

Practical considerations

3-4 month's fellowship in a specialised centre in Europe.

2 types: Clinical elective or Research project

Fellowship budget: max 5,000 Euros

The program started in 2014 with 3 Fellowships awarded. In 2015, 5 awarded.

Fellowship 2016: 6 Fellowships awarded out of 15 candidates

Clinical Fellowships



Mari Abuladze,
Georgia to
Children's
Epilepsy
Hospital,
Kehl-Kork,
Germany



Silvana Kau,
Albania to
Istituto Di
Ricovero E Cura
A Carattere
Scientifico, Italy



Esra Serdaroglu,
Turkey to
Evelina London
Children's
Hospital, UK

Research Fellowships



Barbora Benova,
Czech
Republic to
Great
Ormond St
Hospital,
London, UK



Lucia Gerstl,
Germany to
Great Ormond
Street Hospital,
London, UK



Petra Grđan,
Croatia to
Sommeil &
Explorations
Fonctionnelles
Neu-
pédiatriques,
Lyon, France

In 2017, 6 Fellowships awards will be made available.

Continued...



EPNS Education & Training Report *continued*

EPNS Visiting Teacher

This new EPNS initiative was launched 2016.

Concept: volunteer professor / senior/ distinguished EPNS member recognised expert in a certain field visits nominated host centre in Europe classified by WB in income group 1, 2 or 3 for a short stay of intense teaching (<7 days). Travel and stay up to 2500 Euro is supported by EPNS.

In 2016 two Visiting Teacher awards were granted by the EPNS

1. Professor Linda DeMeirleir from Belgium to visit Romania

The aim of this visit was:

- enhance knowledge of Romania Team for early recognition of metabolic disorders.
- to implement working protocols to be operational in Romania
- to create interdisciplinary network



2. Dr Petia Dimova from Bulgaria to visit to Armenia

The aim of this visit was:

- to establish epilepsy surgery in Armenia



In 2017 two new Visiting Teacher awards will be made available.

Best wishes

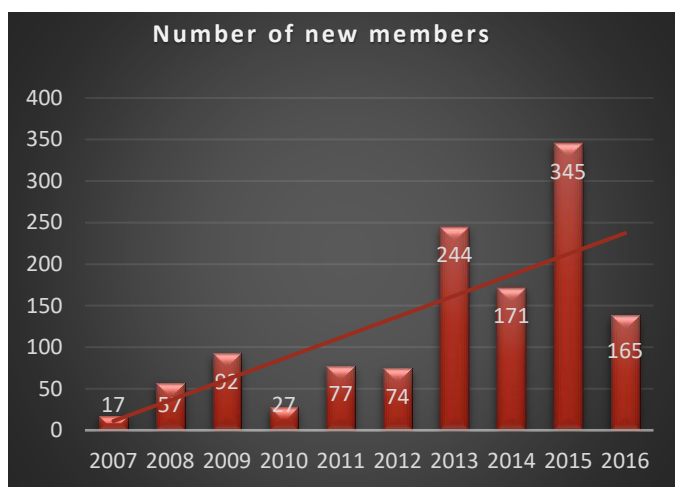
Coriene Catsman-Berrevoets

Chair EPNS Education and Training Committee



EPNS Membership & Public Relations Report

Since taking the role as Chair of this committee I have been delighted to see the total number of EPNS members increase year on year. At this moment, we have a total of 1,120 members. In 2016 it has been a pleasure to welcome more than 160 new members.



New Members

Historically welcome more new members in a congress year as illustrated.

Reasons for joining in 2016:

- 22% NTA/president natl assoc encouraged me
- 21% Through a training course
- 15% Through a Scientific conference
- 12% at ICNC2016 desk
- 10% I saw an advert in the EPNS Journal
- 20% other

Membership Geographic's

Over 900 of our members are in Europe. This this is taken as the region for which the European Office of WHO is responsible. We are delighted however that many of our EPNS members practice outside Europe.



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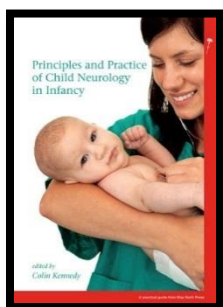
EPNS Membership & Public Relations Report *continued*

Collaborating

The EPNS is keen to collaborate with other paediatric neurology / associated societies in Europe and beyond. We work closely with our colleagues in Europe through the Committee of National Training Advisers, and we have started to form relationships with the following:

- ILAE (International League Against Epilepsy)
- CNS (Child Neurology Society)
- PANDA (Paediatric Neurology & Developmental Association of Southern Africa)
- ACNA (African Child Neurology Association)
- ICNA (International Child Neurology Association)
- Australia and New Zealand Child Neurology Society (ANZCN)
- SSIEM (Study of Inborn Metabolic Diseases and Newborn Screening)

The Society also continues to advertise appropriate meetings on behalf of other organisations on the EPNS and in return the organisation reciprocates.



Free copy of 'Principles and practice of child neurology in infancy'

We have been thrilled to offer our members this publication for a 6EUR postage charge. The recommended retail price is 37.44EUR. Over 700 members have taken advantage of this offer.

EPNS Membership Certificates can be requested by members who have paid their current year annual subscription fee.

Communication

EPNS Flyers also play an important role in advertising the EPNS, and in 2016 approximately 2,500 flyers were distributed at events around the world.



Twitter: @EPNSnews



Email: info@epns.info



Best wishes

Sameer Zuberi

Chair EPNS Membership & Public Relations Committee

EPNS Webmaster Report

Making an up to date of a web site, is at least a bit optimistic, because something new for today is older for tomorrow, especially when we talk about a forum where many people, coming from different cultural and technologic backgrounds, should obtain the same level of services related to our Society.



It is about one year in a half ago when we were taking baby steps updating the website environment to a most friendly one. Since then, a steady increment of hits per day has been recorded, being about a hundred per day by now. We also noticed that besides the frequent visitors of the north and central Europe as well the States, a special increment of visits coming from the southern European countries, a geographic area underrepresented just few years ago, has been recorded. Sadly, we also have been aware that our site has been hit by “robots” trying malicious attempts for obtaining data from our site. These has forced us to promote measures to keep security as a first priority, although in exchange, we have to sacrifice the full access of visitors whose national standards of internet security do no met the criteria of those used where our servers are located.

Then, the new challenges ahead are related to promote our website, not only as a passive EPNS information site, but as a tool for interaction among professionals interested in promoting child neurology health through scientific standards around Europe. We expect to make our site the gate for paediatric neurology social networking in Europe.

In order to reach these objectives, we need the cooperation of the website visitors for knowing which type of information they expected to find in our site. For this reason, we will be very thankful if you ask us for improvements through this page or in social networks.

Best wishes

Francisco Carratalá

EPNS Webmaster



Committee National Advisers (C N A)

The C N A is constituted of advisers selected by the national Paediatric Neurology (PN) societies and associations of all European countries inside and outside the European Union (EU). Normally each country is represented by one member. Therefore, CNA is representative for Europe. The CNA has an executive group consisting of its chairperson, secretary and 3 elected members. In all CNA meetings are present members of the EPNS Board: The president and Chairs of the four main Committees, therefore the information may be passed bi-directionally. **ROLE:** The CNA is a forum for mutual information, discussion and debate on matters relevant to PN.



1. On one side the Committee serves as an advisory group to the EPNS and as a link to the national PN societies. All problems and difficulties of each country concerning PN are being brought and discussed in the CNA meetings and transmitted to the EPNS Board who can act changing the policy of its Commissions per the identified needs in Europe. In this way, the actions of the EPNS Board will always be democratic, open to the voice of the PN societies from all countries in Europe.
2. On the other side, the CNA members have the duty to inform their national PN societies about all the discussion points from the CNA meeting including EPNS courses, EPNS congresses, EPNS membership benefits and fees, keep the EPNS up to date and informed every year about the national PN society and to encourage members of the national PN society to join the EPNS.

On 28 October 2016, the C N A held its 18th meeting in Essen. This was a constructive meeting where the participants agreed to work together to develop a central database relating to PN in each European country. The data in this database may serve to both the EPNS, for taking further actions aiming a homogenous training in the PN in Europe, and to the countries who can improve their PN training concordant to the EPNS Syllabus and the organization of the PN care using successful models from other countries and adapting these to the realities from their country. Data will serve to publish an article in the EJPN showing the current situation of PN in Europe. This article will be a powerful point of reference for countries to use in the future with statistical information about the specialty. Another important discussion point concerned on how more students and trainees can be encouraged to enter the field of PN in the future.

Best wishes

Dana Craiu

Chair Committee of National Training Advisers (C N A)



Training Advisory Board (TAB)

After 2002, when Paediatric Neurology (PN) was accepted at the European level as a sub-specialty of Paediatrics and also of Neurology, in the process of defining the specialty, a European Paediatric Neurology Training Programme (Syllabus) was compiled and accepted by the 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.



In order to push the implementation of a high standard of PN 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. A national training evaluation programme was created in 2004 as an offer to national paediatric neurology societies to voluntarily assess their national training system in comparison with the training programme recommended in the European Paediatric Neurology Training Programme (Syllabus). 13 visits have been done in 12 countries starting 2007.

The new development of the economic climate in the world changed the concept in the TAB working methods, the visits being very difficult to evolve.

Interactive web-based evaluations or assessment during National PN Societies Conferences have been performed. In 2016 this was the case of Ukraine where the Ministry of Health intended to dissolve PN and include it into the Pediatrics training programme. A letter from the TAB and a visit of TAB Chair, Dana Craiu, in Kiev convinced the politically decision factors present at the National PN Conference to maintain PN as a separate specialty and to increase duration from 2 months to 5 months of training. Still work has to be done to insure a proper training in PN in Ukraine. For the years to come, new strategies and ways of influencing and insuring a homogenous training in the European countries should be imagined.

Currently TAB is formed of: Dana Craiu (Chair), Lieven Lagae, Peter Baxter, Coriene Catsman, Finbar O'Callaghan, Banu Anlar, Nina Barisic, Katalin Hollódy, Maja Steinlin member of the European Academy of Childhood Disability and 1 Member of the Neurology Board.



Best wishes

Dana Craiu

Chair Training Advisory Board (TAB)



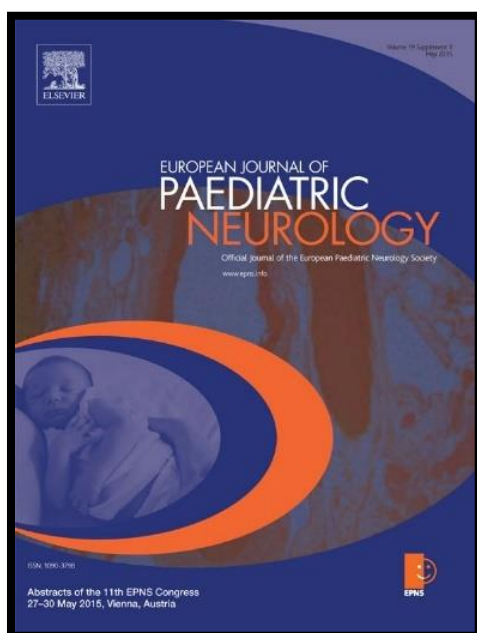
European Journal of Paediatric Neurology Report (EJPN)

This is the official Journal of the EPNS, managed by an international team of Editors and I am honoured to be the Editor-in-Chief.

The EJPN is a multi-disciplinary journal publishing exciting clinical and experimental research in this rapidly expanding field. High quality papers written by leading experts encompass all the major diseases including epilepsy, movement disorders, neuromuscular disorders, neurodegenerative disorders and mental retardation.



This year the Journal is celebrating its 20th year of publication!



It has established itself as a leading publication in the field, as evidenced by the following:

- Highly cited: impact factor consistently around 2 and there were over 1500 citations of articles last year
- Rapid publication: on average, it now takes on average under 25 weeks from first submission to online publication
- Widely read: over 200,000 full-text articles downloaded in 2015
- Easily accessed: members can access via a dedicated homepage (via desktop or mobile devices), and can set up a table of contents alert for each issue
- High quality: submissions increased by 50% in 2016. We have to reject around 70% of

submissions.

As part of their annual subscription fee, EPNS members receive 6 issues per annum. In 2017 we will devote a unique special issue to cutting edge technology and therapies in the field of Neuromodulation in Childhood

Best wishes

Sameer Zuberi

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 Annual Subscription Fees for 2017

	electronic-only EJPN	printed copy of EJPN
Category WB4A: Member from World Bank Class 4 nation not mentioned in Category 4B	130 Euros	160 Euros
Category WB4B: The following World Bank Class 4 nations: CROATIA, CYPRUS, CZECH REPUBLIC, ESTONIA, GREECE, HUNGARY, LATVIA, LITHUANIA, MALTA, POLAND, PORTUGAL, SLOVAK REPUBLIC, SLOVENIA, SPAIN	65 Euros	95 Euros
Category WB123: Member from World Bank Class 1, 2 or 3 nation	30 Euros	60 Euros
Category Trainee: Trainee member from any nation	20 Euros	50 Euros

Contacting the EPNS



Email info@epns.info



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



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

Joining the EPNS

There has never been a better time to join!

If you are not already a member, please think of becoming one. By doing so you join a rapidly 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 on-line through our website <http://www.epns.info/> Please scroll down the home page until you see the orange **'BECOME A MEMBER'** button. Please click on this button to get the application form. Once you submit the form, you will receive an email acknowledging receipt. Our EPNS Membership Secretary will then get in touch with you shortly afterwards to formally welcome you to the Society.

