Paediatric Nursing Associations of Europe
Athens, Greece
Notes 31st May 2018

Venue: Faculty of Nursing, National & Kapodistrian University of Athens,
123 Papadiamantopoulou Street, Goudi, Athens, Congress room.

Time: 09:00 -14.00

Attendees
Vasiliki Matziou, Greece [VM]
Barbara Boutopoulou, Greece [BB]
Dr Eleni Kyritsi-Koukoulari, President Hellenic National Nurses Association (HNNA) & Advisor Paediatric Nurses Sector Greece [EKK]
Pantelis Pedikaris, President Paediatric Nurses Sector of Hellenic Nurses Association, Greece [PP] [Host]
Ayse Ferda Ocakci, Turkey [AFO]
Majda Ošir, Slovenia [MO]
Janja Gržinič, Slovenia [JG]
Immacolata Dall'Oglio on behalf of Italian National Federation of Nursing Professions Orders [ID]
Ingrid Hankes Drielsma, Dutch Association of Paediatric Nurses, Netherlands [IHD]
Caroline Roberts-Quast, Dutch Association of Paediatric Nurses, Netherlands [CRQ]
Kristina Kuznik, Croatian Nurses Association of Paediatric Nursing Society [KK]
Dragica Beštak, Croatian Nurses Association of Paediatric Nursing Society [DB]
Jorunn Tunby, Norwegian Paediatric Nurses Association [JT]
Katrin De Winter, Paediatric Nurses Association, Belgium [KDW]
Karen Vansteenkiste, Paediatric Nurses Association, Belgium [KV]
Ivona Mikulenko, vice President, Paediatric section of the Czech Nurses Association [IM]
Dr. Gudrún Kristjánsdóttir, Professor, Icelandic workgroup of paediatric nurses in Iceland [GK]
Karin Bundgaard, Paediatric Nursing Association, Denmark [KB]
Conni Andersen, Paediatric Nursing Association, Denmark [CA]
Helena Wigert, Swedish Paediatric Nurses Association, Sweden [HW]
Mrs. Sofia Abreu, Secretary of the Professional Specialty College of Infant Health and Paediatrics Nursing, Ordem dos Enfermeiros, Portugal [SA]
Mrs. Filipa Barbosa, Professional Specialty College of Infant Health and Paediatric Nursing, Ordem dos Enfermeiros, Portugal [FB]

Apologies
Frauke Leupold, Berufsverband Kinderkrankenpflege, Germany [FL]
Fiona Smith, Royal College of Nursing, United Kingdom [FS]
Jane Coad, Coventry University, United Kingdom [JC]
Orsola Gawroski on behalf of Italian National Federation of Nursing Professions Orders [OG]
Catherine Sheridan, Irish Nurses & Midwives Organization (INMO), Ireland

Notes 31st PNAE meeting - Athens - may 2018
1. **Welcome & introductions**

VM, Host and chair of the scientific committee, welcomed attendees to the meeting.

IHD chaired meeting, minutes noted by KDW and CRQ. Short round of introductions followed.

2. **Apologies – see register**

3. **Update of Paediatric Nursing in Greece**

Presentation to be given during one of the keynote speeches during the congress.

4. **Matters arising from notes of meeting October 2017**

No comments on previous notes.

4.1 **Written update for website**

IHD: Please check all information from your country including the given link of your association on the website and mail FS if needed. Belgium and Italy have done so and noticed they are not on the website anymore. CRQ has sent 2 mails already as the link for the Dutch part is incorrect. Each country to check the name and email address for the key contact as above and the weblink for their association and advise FS if information needs amending – **Action all**

Updates to key contacts and weblinks to be placed on PNAE website when received –

FS.

4.2 **Congress 1st & 2nd of June 2018 in Athens**

PP Announcement: Annette Kennedy, President of ICN will be present at the opening of the congress. PP presented a brief summary of the work done in preparation of the congress. The work started after the last congress in Oporto. PP expressed thanks to members who contributed to the organisation of this congress. Over 350 participants are registered and are expected to attend the congress. This includes speakers, chairs and students. There will be 3 prizes for best research papers that are ready for publication. Attendees congratulated the Greek colleagues for organizing the congress. Presentation available on request (PP).

**NB: Agenda point 11 brought forward to 4.3**

4.3. **Future priorities, challenges and changes**

IHD presented the origin of the PNAE (presentation available on request).
- Birth International Paediatric Nursing Association (IAPN) in 1998.
- Birth Paediatric Nursing Associations Europe commenced April 2003.
- 32 countries now participate actively.

Challenges and changes in role of coordinator and deputy.

IHD: The RCN has stated that after 10 years they can no longer provide the role of coordinator of the PNAE. They do want to want to continue as participants within the PNAE. The role of FS as coordinator ends in 2018. A new coordinator of PNAE has to be appointed. IHD asks all members for a consensus on how to proceed further. New working method in role of deputy needed? Communication
needs to be more effective and all members of PNAE have to take equal responsibility. Discussion pursued on how to continue the PNAE and this was followed by a vote.

- **EKK Greece**: would like to make an official step from network to an association, however will stay in the network of the PNAE.
- **IM: Czech nurses association**: may not continue as an association in the future.
- **IHD**: The Netherlands will not participate in a PNAE association. IHD points out that PNAE is a network. *PNAE stands for Paediatric Nursing AssociationS of Europe* Attendees represent their associations. An association is a formal independent body with an official board and regulations. By being a member of an association membership fees will have to be paid. Travel expenses would therefore be at the cost of one association.

**Vote 1: Do members want to continue with PNAE?**

**Results**: all attendees agreed.

**Decision**: All members wish to continue with PNAE.

**Vote 2: Does PNAE stay a network of associations or become an association?**

**Results**:
- **Greece**: voted for an association.
- **Other 12 countries**: Voted against an association and agreed that PNAE stays a network of associations.

**Decision**: PNAE stays a network.

**Vote 3: What is a realistic timeline to fulfil the role of coordinator within the PNAE?**

**Results**:
- **Greece, Sweden, Belgium, Norway and Iceland** - 4 years. It’s important that it follows the timeline of a congress.
- **Portugal: Slovenia, Croatia, Italy, Denmark, Turkey, Czech Republic and The Netherlands** - 4 or 5 years.

**Decision for now**: PNAE coordinator for 4 years.

IHD points out that because PNAE is a network we don’t need a board to switch coordinators. If the experience shows that 4 years turns out to be too short, this will be discussed. If a coordinator wants to stay on after 4 years this should also be possible and discussed with all members.

**Vote 4: Is it necessary for a coordinator and deputy to come from the same country or preferably from different countries?**

**Results**:
- **Slovenia**: depends on the available communication possibilities.
- Croatia, Denmark, Belgium, Norway, Turkey voted for different countries.
- Sweden: different countries. Iceland, Norway, Sweden and Denmark are part of the Nordic association. There is good communication.
- The Netherlands: Different countries providing communication is effective.
- Czech Republic: Different countries providing means of communication is possible.
- Iceland: Different countries. Important that there is an adequate overlap when roles are handed over.
- Italy: No definite opinion however it would depend on resources available. But probably from different country could be better.
- Greece: Both roles preferably from same county for ‘better’ coordination. Experience shows it is more effective for coordination.
- Portugal: Different countries. Portugal has elections every 4 years and this period ends in 2019. In 2020 there may be another representative.

Decision: Majority of attendees feel that a coordinator and deputy coordinator need not come from the same country.

- BB: The main goal of PNAE is to be a voice within Europe for sick children. Coordinator has to keep in mind that he/she has a serious job in Europe.
- IHD: Role of coordinator is not achievable if a representative doesn’t attend all PNAE meetings or he/she has to make sure the deputy can be there. The role of FS from within the RCN was tremendous and time was given for this role by the RCN. Other associations may not have these resources. Biggest challenge is that all representatives have to take responsibility to meet deadlines to make the role of coordinator achievable. This means all members meet deadlines, hand over information when asked and inform a host when asked as to who is attending the meeting, dinner etc. …-

- All members present agreed.

Question: Who (which country and representative) is willing to be next coordinator?

- The Netherlands: Not available. Co-founder and active for many years.
- Greece: not ready due to internal challenges
- Denmark: would like to wait 2-4 years. Will need to discuss this with their association first
- Croatia: not available. Think it should be handed over to younger professionals.
- Slovenia: Amount of work involved is not really evident, not sure. It could be discussed but would prefer a larger country to contribute.
- Portugal: difficult due to election times (4 years). Would like more experience.
- Iceland: has a small association. Not presently available, would like more experience. Important issue is that taking over requires a fair degree of linguistic skills.
- Norway: elections are next year. JT will no longer be a representative. Norway could coordinate together with another Scandinavian countries later. Will discuss this with members at their general spring meeting 2019.
- Italy: could be possible after their next elections. Needs to be discussed with it’s own National Federation of Nursing Professions Orders. Nevertheless Italy is
available for the role of deputy, as soon necessary. TIP: need to connect with younger members.

**Belgium:** Not possible at present due to changes in status of paediatric nurses in Belgium. Will discuss it with their association

**Sweden:** not possible at present.

**Czech Republic:** elections due next year. If its nurses’ association continues IM has given her commitment to attempt to continue the coordination of the PNAE.

**Action:**

The Netherlands prepared to assist new deputy and coordinator. IHD will ask Corry to stand by as deputy for now. IHD can assist with transition of coordinator. IHD.

Adjustments: FS might be able to help the new coordinator for this year.

All members take full responsibility to meet deadlines, hand over information when asked – ALL topic on the agenda for the next meeting - FS

**Discussion: about the continuation of the website if RCN can’t**

-**PP:** experience as administrator for HNNA discussed: To do this administration will require a salary. One needs to be familiar with website design.

-**GK:** Experience in Iceland: Free from pearl.net – could be done by younger members.

-**IDO:** Will ask nursing orders of Rome or at national level if they could host a PNAE webpage if that would be necessary. Will ask hosting page of families or children.

-**IHD:** Website can’t move from 1 country to the next every term of 4 years. If RCN continues to host website what does this mean? At present requirements are not clear. Who can fill the website if it stays at RCN and FS is no longer coordinator.

**Action:**

-Getting clarification from RCN about continuation of website. - Corry van den Hoed-Heerschop.

-Looking for information on hosting a website: costs, possibilities for webpage on existing websites. Suggestions to be sent to KDW – ALL

-Every country is responsible for updating information. Not all given info has changed on the website at this point. – FS. To place topic on the agenda for the next meeting - FS

**4.4 Workforce and recruitment**

Reviewing and updating nurse education for paediatric nursing position across Europe discussed.

**Czech rep:** There will be a bachelor degree for paediatric nurses by 2019.

**Turkey:** Have a 4 years bachelor programme as well as a masters and PHD programme.

**Slovenia:** Have general bachelor programmes but not specifically in paediatric nursing
**Denmark**: Have a general bachelor programme. Degree in paediatric nursing in progress.

**IHD**: The position statement paediatric nursing in Europe and education programmes needs to be revised/updated (see website RCN/PNAE for statement.

- See notes from SC sent after the meeting

**Action:**

Slovenia (MO) & Belgium (KDW) offered to do this. All additional information about paediatric nursing in Europe and education programmes can be sent to MO & KDW – before end of June **ALL**

Timeline: To be received by the end of June and dispersed by MO & KDW beginning of July 2018 **via FS**.

Participants are expected to prepare themselves on the received document prior to the next meeting. **ALL**

The revision will be placed on the agenda for the next meeting - FS

**Advanced Nursing Practice**

This was discussed at last meeting in Reykjavik, Iceland. Before making a survey, definitions need to be clear and agreed on by all members.

**Action:**

Italy (IMO): accepts this task. Will do this by means of Google forms.

Make up potential questions for survey on ANP- For document: See point 8 notes last meeting Reykjavik

Timeline: end of June 2018 **by IMO via FS**.

Topic will be placed on the agenda of the next meeting – **FS**.

6. **Potential for Pan European standards of care/evidence-based protocols are European reference standards of care based on evidence.**

IHD presented the “European Standards of Care for New-born Health project” initiated and coordinated by the European Foundation for the Care of New-born Infants (EFCNI). The project started in April 2014 at the EU parliament in Brussels and expected to be completed and presented to the EU parliament at the end of 2018. All healthcare societies, European parents’ organisations and professionals support the development of these European “reference” standards. There are 220 TEG members from 35 countries working in close collaboration to develop more than a hundred “reference” standards of care for a broad area of topics in newborn health. All based on developmental and family integrated care. Every country within Europe will be responsible for translation of these standards and implementation at national level. The presentation is not available but all information can be found on the website: ([www.EFCNI.org](http://www.EFCNI.org)) [www.newborn-health-standards.org](http://www.newborn-health-standards.org)

7. **Safeguarding children and young people**

After discussing this topic at the last meeting in Reykjavik, attendees agreed a survey was necessary. **FL** was willing to draft questions and circulate before this meeting and wanted
to do this together with the European research group. (About this topic see presentation of Maria Brenner at 30th PNAE meeting in Iceland 2017). Due to circumstances FL was not able to prepare this before this meeting. FS sent an email stating that it’s too early for the PNAE to work together with other organisations. PNAE has to first define terminology and agree on definitions on safeguarding. All members should agree prior to future actions.

Action:
Set up questions about safeguarding young children in preparation of a survey.

IHD will contact FL. to check if she’ is able to prepare some questions.

If not this will be done by IHD & CRQ.

Additional information about Safeguarding young children can be sent to IHD & CRQ - ALL

Timeline: end of June via FS.

Members prepare themselves and discuss the results of the questionnaire at the next meeting. Topic on the agenda for the next meeting – FS

8. School Nursing
SA - Notes from previous meeting were very helpful. No need’ to discuss this further.

9. Shared record keeping between nurses and families
IDO highlighted the meaning and questions of shared record keeping. (Presentation on request).

Discussion and reactions:

- The Netherlands: App development in progress so parents can share their stories. It is a closed part of record. Parents have spoken up that nurses gave their own interpretation to what parents write down in their diary. Nurses have to ask parent’s permission to document about them and do this together with parents. Access to computer file in presence of nurse or doctor so they can explain the information.

- Denmark: Records are accessible by patients > 15 yrs old and parents access to EPD by means of an account/security check. The nurse brings the records to room and first ask parents how they see the condition of their child. After enquiring condition of child, the documentation is read together with parents.

- Iceland: Research in progress re how to manage diaries. By law: One can’t write about parents in record except if necessary. Participating in a survey in PNAE would be difficult. A discussion on this topic would be a better solution. There is evidence from Canada, concerning shared records.

- Greece: has a different situation. There is no official way of sharing records with parents. Parents have to make a special request to receive copies of the records.

- Norway: same as Denmark. Parents can’t write in records. In paediatric wards, parents write together with nurses.

- Croatia: access to paper records and access to computer file in presence of nurse.

- Slovenia: by request, in presence of nurse or doctor so they can explain the information.

- Portugal: nurse will explain everything. Parents can read notes but aren’t allowed to see digital documentations. Only on request. NIDCAP centres involve parents to write notes.

- Turkey: Parents can see documents on request. Patients can look in the computer, not write notes.
Belgium: Possible for all parents to read records, not write. Not always digital but is next step.

Czech Republic: have medical electronic record. Parents read written records, not write.

Conclusion: Regions and countries show different situations. We have to keep discussing this topic discuss deeply again. Workgroup with representatives from different countries are needed: Nordic group, Southern and middle Europe.

Considerations points 9&10:

1. Privacy
2. Sharing documentations differs per country.
3. Rights of parents and neonates are part of Family integrated care standard

Action:

• To start a working group (3-4 members) about shared record keeping from within different settings: Italy/ Greece/ Denmark: goal: discussing questions for a survey – IDO
• All additional information about shared record keeping can sent to IDO - ALL
• To place on the agenda of next meeting - FS

10. Record keeping & documentation
Point 9 and 10 were discussed together – see point 9.

11. See point under 4.3

12. Any other business
- Slovenia: next stage of IV home therapy to prepare a document, question and send this to CYRQ
- Iceland: not able to be present in October, apologies for next meeting
- Belgium: update point 13 notes Reykjavik: Points of view about transmural care for children in Belgium. Points of view were supported by attendees from meeting in Reykjavik. The document will be presented to the Belgian government. Update next meeting in Prague.
- Sweden: Post graduate students now have a full salary (50% placement and 50% for education)

Action:
• Update Belgian situation about transmural care for children – KDW
• place topic on the agenda for the next meeting: update Belgian situation about transmural care for children (KDW) – FS

13. Future meeting dates/venues and locations

• 18th and 19th October 2018 – Prague, Czech Republic
• Czech Republic: a possible visit to Proton Therapy Centre (therapy for children with cancer, unique in Europe), more news about this in august.
• Meeting in hotel – special prices were received.
• Actions see nr 11 in action points. Program and actions needed before 31 st of August 2018 – All
• 23rd & 24th may 2019– Madeira, Portugal – confirmed by SA
• 17th and 18th October 2019 – Zadar, Croatia – confirmed by KK

To be confirmed
• Spring 2020 including 2-day congress - Estonia - attendees met two lovely girls during the congress – IHD & CRQ made contact and shared information. Both persons will be present on our meeting in Prague.
• Autumn 2020 – Ljubljana, Slovenia
• Spring 2021 - Leuven `Lier, Belgium
• Italy could host the PNAE congress in spring 2022 in Rome. IDO will ask to the National Federation in order of this proposal.

NOTE

- If documents are circulated with request for comment/agreement and no response is received it will be assumed that there is agreement.

*Please ensure receipt of emails is confirmed.*