

**23rd Meeting
Paediatric Nursing Associations of Europe**

**Oslo, Norway
Notes 28th and 29th April 2014**

Attendees

Siw Fossan, Norwegian Paediatric Nurses Association [SF] [Host]
Jitka Voříšková, Head of the Pediatric section of the Czech Nurses Association [JV]
Ivona Mikulenková, Pediatric section of the Czech Nurses Association [IM]
Frauke Leupold, President Berufsverband Kinderkrankenpflege, Germany [FL]
Corry van den Hoed-Heerschop, Dutch Association of Paediatric Nurses, Netherlands [CvH]
Caroline Roberts-Quast, Dutch Association of Paediatric Nurses, Netherlands [CRQ]
Madeleine Collombier, Association Nationale des Puéricultrices Diplômées et des Etudiants [MC]
Orsola Gawronski, on behalf of Italian Nurses Association [OG]
Evalotte Morelius, Swedish Pediatric Nurses Association, Sweden [EM]
Katrín De Winter, Paediatric Nurses Association, Belgium [KdW]
Karen Vansteenkiste, Paediatric Nurses Association, Belgium [KV]
Ayse Ferda Ocakci, Turkey [AFO]
Fiona Smith, Royal College of Nursing, United Kingdom [FS]

Apologies

Dragica Bestak, President Croatia Nurses Association of Paediatric Nursing Society [DB]
Kristina Kuznik, Vice President Croatia Nurses Association of Paediatric Nursing Society [KK]
Immacolata Dall'Oglio on behalf of Italian Nurses Association [ID]
Martha Böhm, Paediatric Nurses Association, Austria [MB]
Britt Marie Ygge, Swedish Pediatric Nurses Association, Sweden [BMY]
Ingrid Hankes Drielsma, Dutch Association of Paediatric Nurses, Netherlands [IHD]
Anna Barbara Schlüer, Switzerland
Anne-Marie Bangels, President Paediatric Nurses Association, Belgium [AMB]
Claus Sixtus Jensen, Paediatric Nursing Association, Denmark [CSJ]
Karin Bundgaard, Paediatric Nursing Association, Denmark [KB]
Pantelis Pedikaris, President Pediatric Nurses Sector of Hellenic Nurses Association [PP]

1. Welcome/introductions

Attendees introduced themselves to each other.

It was noted that the hospital visits arranged in Oslo were successful.

2. Update of Paediatric Nursing in Norway

SW highlighted that the Norwegian Paediatric Nurses Association was established in 1973. Members include paediatric nurses but also others working with children and young people. There are 650 members of the Association with 17 local groups around the country. The Association has a central board. The Association aims to empower nurses at local level, to primarily work at national level but also recognises the need to keep in touch with Europe and International issues. There is a need to raise the profile of paediatric nursing and to reinforce that children and young people are different and are not just small adults. Nurses need specific training to work with children and young people. There is a need to ensure children and young people's voices heard at every level. Degree nurse education programmes do not include as much paediatrics content as is needed. The Association also promotes additional paediatric nursing training at post graduate

level and host an annual conference in different locations across Norway. There are usually 120 attendees. Local groups hold seminars and theme night at their hospital locally. Central board has a wide geographical spread and different experience i.e. newborn, oncology, adolescent etc where possible.

3. Matters arising from notes of meeting November 2013

3.1 *Written updates for website*

[\[http://www.rcn.org.uk/development/communities/specialisms/children_and_young_people/forums/other_forums_and_groups/paediatric_nursing_associations_of_europe\]](http://www.rcn.org.uk/development/communities/specialisms/children_and_young_people/forums/other_forums_and_groups/paediatric_nursing_associations_of_europe)

FS advised that some information had been received. Some countries had yet to advise of relevant website links, or the named contact for the website and for communication. The name of each Associations name in own language to be placed on PNAE webpage if provided and also contact email addresses if advised

Action:

- Each country to email FS the name and email address for the key contact as above and the weblink for their association – **All**
- Key contacts and weblinks to be placed on PNAE website when received – **FS**
- Key contact to cascade information, agenda's and papers within their own country/Association as required - **All**

3.2 *Future PNAE congresses and 3rd PNAE congress*

It was noted that information including themes and invited speakers had been submitted to eic according to timelines. Organising committee and scientific committee members had also been identified. FS had advised PNAE members in January that eic had moved the venue for Europaediatrics from Rome to Florence. Eic subsequently notified FS in February that they had decided not to progress with the organisation of a 3rd PNAE congress alongside Europaediatrics in Florence.

Attendees discussed organisation of future congresses. IMD had offered the possibility of linking with Italian Nurses Federation 5th-7th March 2015 or to organise an event with the paediatric nurses association in June. MC reported that the Association of paediatric nursing could possibly host in Marseille in 2015. Portugal had also offered to organise a PNAE congress in June 2015.

Following discussion it was agreed that a PNAE meeting would be held in Rome in June 2015 as previously scheduled. IDO had indicated the possibility of holding a one day paediatric nursing seminar programme with the Italian paediatric nursing association. Potential dates suggested:

- PNAE meeting 4th June, one day seminar programme for paediatric nurses 5th June, with hospital visits scheduled for afternoon of 3rd June 2015
- Or**
- PNAE meeting 11th June, one day seminar programme for paediatric nurses 12th June, with hospital visits scheduled for afternoon of 10th June 2015

PNAE members attending the PNAE meeting in Rome would be available to participate and speak where requested at the one day seminar programme for paediatric nurses.

The possibility of aligning PNAE congresses with national paediatric nursing association congress every 2 years discussed, starting from 2016 in Paris.

Action:

- OG to discuss with IDO the above proposal and to advise FS of outcome and selected dates – **OG/IDO**
- To discuss with colleagues the potential for aligning a PNAE congress with the national paediatric association congress in Paris - **MC**

3.5 *RN4CAST, recruitment and competence of nurses*

BMJ had sent apologies. Item deferred to next meeting.

Action:

- Send written update or verbal update with representative from Sweden if unable to attend - **BMJ**

4. **Family presence in paediatric and neonatal areas**

FS discussed the findings to date. It was noted that Iceland and Croatia had indicated they would be sending information through in due course. Once received information would be added to the collation.

The draft PNAE position statement discussed and amendments to be made. The revised version of the position statement to be circulated to attendees for review.

Action:

- Review revised position statement by 12th May 2014 – **all attendees**
- Further amendments to be made as required - **FS**
- Final position statement, summary of collated findings and covering letter to be sent to PNAE members for translation and cascade within their country - **All**

5. **Child Euthanasia law in Belgium**

KV highlighted the new law recently introduced in Belgium (see attached). Issues discussed. Attendees highlighted:

Sweden

Discussion in neonatal intensive care-There has been a specific case when a doctor was prosecuted. Issues include concerns about the life of medication and withdrawal of life supporting treatment.

Czech Republic

Euthanasia has been discussed in respect of adults. Palliative care is a huge topic and the need for good pain relief. Hold concerns about misuse of law if legislation was introduced.

Norway

Euthanasia has not been widely discussed. Similar scenarios like Sweden. Doctors are often afraid of talking to children about these issues. Provide high dose pain relief and sedation given to children.

Germany

Problems related to history. Active Euthanasia banned for all ages. Emphasis is on pain relief and promotion of palliative care. Palliative care has improved, There are special paediatric palliative care teams. Team discussion and engagement of ethics committee, when withdrawal of therapy/treatment is an issue. Decisions on all treatment – not only in case of life-limiting conditions - by parents, for 14-18 year olds look at individual child and developmental stage.

France

Questions raised about what happens if the child requests euthanasia but parents say no.

Netherlands

Reported concern about the lack of DNR. Not sure the law in Belgium will have any effect and may make the situation more difficult. It may lead to more discussion. It was noted that after 16 parents do not need to agree, whereas for 12-16 years parents need to agree.

Turkey

The subject of Euthanasia has not been discussed in Turkey. The emphasis is on pain relief and palliative care.

UK

Euthanasia has been debated in relation to adults. The Royal College of Paediatrics and Child Health has developed guidance about the withdrawal of life saving treatment. The emphasis in the UK is on pain relief and palliative care. There are instances of where young people have made decisions not to have further active treatment. Usually the courts are involved in these instances.

Following discussion it was agreed that PNAE would maintain a neutral position on this issue but would observe the implementation of the law in Belgium.

Action:

- Keep PNAE members posted on the introduction of the law – **KV/KdW**
- To place Do Not Resuscitate orders on a future PNAE meeting agenda - **FS**

6. Education programmes: mapping of learning outcomes

KdW presented work to date to develop 13 learning outcomes using PNAE appendix A (see attached presentation). Need to identify values, attitudes and behaviour indicators. EM highlighted a pertinent chapter in a paediatric nursing book in Sweden.

Action:

- Keep PNAE members updated on development of indicators - **KdW**

7. Preparing paediatric nurses for care of children at home

Attendees discussed the issues and reported:

Netherlands

There are an increasing number of chronically ill children being cared for at home. Paediatric nurses complete degree level education programme and then a specific

post graduate programme for paediatric nursing. The content of the latter is highly hospital orientated. Most of the children at home are cared for by home care teams who are task orientated

Belgium

As per the Netherlands home care nurses are not paediatric nurses. They may have had some paediatric nursing preparation. The home care nurses are task orientated and are not trained to care for children at home. one hospital has the dream to follow the child and for paediatric nurses to be able to provide all round care whatever setting.

Turkey

Children with long term conditions are seen in outpatients. In some special cases nurses give home care.

Italy

Services provided stem from the paediatric hospitals. Nurses from the hospital will provide care to the child at home. This provision is not well developed. Due to payment systems there is variable provision.

Sweden

Hospital home care is provided by paediatric nurses from the hospitals. They have received education preparation to provide care in whatever context.

Czech Republic

Many children with long term conditions may remain in hospital. Some parents take children home but there are no paediatric home care nurses or agencies for children only for adults. The adult home care nurses provide care for children.

Norway

Like Sweden home care is provided from the hospital. This service has just started.

Germany

Home care teams are privately run. Some are specialised on children. There is the problem of financial return, because of higher costs in comparison to services for adult and elderly people. There are attempts to build regional networks. All Nurses need theoretical and practical training for home care during their basic nursing education. Students for paediatric nursing ideally in paediatric services but not enough capacity for all. Sometimes children are cared for by adult teams.

France

There are special teams that provide home care but they are not paediatric nurse specialists. There is a focus on providing more care in the community and a new education programme has been introduced – advanced practice in oncology practice (adults and paediatrics)

UK

There are community children's nursing teams across the UK providing care and support to children at home with acute, long term conditions, with disabilities and complex health care needs, and for palliative care and end of life care. There is however variability in service provision. Children's nurses today are educated to

provide care to children and young people in community and primary care settings, as well as acute care in hospitals. At post graduate level nurses working in community settings need additional knowledge, skills and competences to practice at an advanced practice level and many complete modules related to advanced clinical decision-making, leadership and nurse prescribing.

Attendees discussed and agreed that the initial paediatric nursing education programme should encompass the knowledge, skills and competence to enable the paediatric nurse to provide care across all settings. It was recognised that nurses may subsequently need additional education preparation in advanced clinical decision-making, leadership and nurse prescribing dependent on their role.

9. **Any other business**

CvH gave apologies for the next meeting. It is likely that IHD and CRQ will attend from the Netherlands

FL enquired about breast milk banks and advised of a private person promoting and selling of breast milk via Internet, safety only recommended not compulsory.

IM enquired about JCI international accreditation. It was noted that accreditation processed highlight professional development and multidisciplinary team working.

EM highlighted the content of a book about nursing metrics and the measurement of the quality of nursing care for paediatric nursing i.e. drugs, intravenous medication and pain relief

10. **Future meeting dates/venues and locations**

Attendees discussed future venues and agreed that where possible meetings should be held in different countries to those that have already held a meeting. Members requested that FS explore the potential for a PNAE meeting to be held in Iceland in 2017

- 13th and 14th November 2014 – **Porto, Portugal**
- June 2015 **Rome, Italy (dates to be confirmed)**
- Winter 2015/January 2016 – **Athens, Greece**
- Spring/Summer 2016 – **Paris, France**
- Winter 2016 – **Istanbul, Turkey**

Action:

- Advise FS of attendance at the November 2014 meeting- **All**
- Explore the potential for a PNAE meeting in Iceland in 2017 – **FS**

Please advise FS if you are interested in hosting a meeting - all

PNAE meetings are held in different venues/countries to enable as many representatives from Paediatric Nursing Associations/National Nursing Associations to attend and participate in activities. We appreciate that financial implications of travel and accommodation may prevent several members from attending PNAE meetings. If your country has not yet attended a PNAE meeting but you would be interested in hosting a meeting in your Nursing

Association/Country please contact Fiona Smith – Fiona.smith@rcn.org.uk
ASAP

16.45 Meeting closed.

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.***