

## **2<sup>nd</sup> Annual General Report of the European Cystic Fibrosis Society Nurse Special Interest Group (ECFS NSiG),**

**To be presented at Annual General Meeting Belgrade 6<sup>th</sup> June 2018**

History:

At the ECFS in Basel in 2016 the existing International Nurse Specialist Group (INSG) voted to reform and affiliate to the ECFS as a Nurse Specialist Interest group (ECFS NSiG). This is the second Annual Report from the ECFS NSiG: The current committee comprises

- Chair: Dr Kath MacDonald, RN/Prof.Doc, H&S.Sc.,Scotland, UK
- Secretary: Ann Ramen, RN/CNS, Belgium
- Treasurer:Signe Fog Sønderup RN/CNS, Aarhus Denmark
- Committee member:Majda Ostir RN, UKCL, Pediatric clinic, Ljubljana, Slovenia.
- Committee member: Silvia Rodriguez Torres - CF Centre, Barcelona
- Committee member: Yulia Gendler RN MSc, CF Nurse specialist, Israel

The aims of the NSiG are as follows

### Aims

- To advance education, research and clinical skills for the improvement of cystic fibrosis nursing and care
- To create a meeting place for other CF nurses to share experiences and best practices and develop a community of practice.
- To prepare the nursing pre conference programme at the ECFS

### Objectives

- To disseminate evidence- based best practice
- To collaborate on research and audit to promote and evaluate quality CF Care
- To promote, apply and contribute to further development of the standards of care for cystic fibrosis
- To work interprofessionally with other disciplines to further enhance cystic fibrosis care
- To provide educational opportunities for CF nurses to support their continued professional development

### **2017 conference Seville**

Over 80 nurses attended this meeting which was evaluated as a great success, with the exception of the venue. We had requested a room with tables for small group discussions but were allocated a 300 seater lecture theatre. However we made the best of it and still managed to achieve small group working, larger discussions and a series of really interesting workshops.



*Seville 2017, our new committee and outgoing co-chair. From Left: Yulia Yendler, Ellen Hunstad (outgoing) Ann Raman, Silvia Rodriguez Torres, Signe Fog Sønderup, Majda Ostir, Kath MacDonald*

## **Presentations and workshops**

Theresa Chinn MBE, Social media Consultant and nurse and founder of WeNurses (@WeNurses) gave a lively presentation on the use of twitter and social media as a means of networking and education. People were then given the opportunity to try it out and post photos and tweets to #ecfsnurses. Please continue to use this tag for the upcoming conference and any ongoing communication and networking between the group members. We are keen to grow this form of communication between our members.

Theresa's presentation was followed by two National presentations from Silvia Rodrigues Torres (Barcelona) and Pedro Garcia (Seville).

The afternoon session started with Louise Taylor and Kate Gent from Canada who gave a thought provoking presentation around some difficult ethical issues and complex cases, including referral for transplant and end of life care.

Finally Ann Raman spoke to the group about her experiences of attending the first Middle East CF conference in Oman in February. Her reflections included some thought provoking facts about life expectancy, large families with up to five children with CF, lack of specialist resources including medicines and CF nurses and long distances to travel for care. Ann hopes to return next year.

## Website development and update

All of the presentations from Seville can be found on our updated ECFS web pages and we would encourage members to access this resource

Feedback from the Seville day was as follows:

- *Very well done – love the group discussion forum. Great to hear what others do and how that centres cope with similar issues. Good to have 1 or 2 main topics for the day rather than too much information crammed into the day. Thank you*
- *An excellent day – really appreciate all the hard work to organise such a good day. Thank you!*
- *Excellent first session. Great session. Thought provoking and engaging. Pushing me into the 21st century!!*
- *Enjoyed discussions on ethical and non -health care issues*
- *Election form committee members –enjoyed the individual presentations*
- *Very good day. Useful networking opportunities*
- *Room was inappropriate*
- *Agenda was fabulous. Obviously room layout was disappointing*
- *It's been a good day, but a bit long*
- *It was a very good day. It was a very rich day of experiences of nurses*
- *A bit messy. The last session with end of life care was best*
- *Organisation for the group was ok.*
- *Different seating would be best for more interaction*
- *The room was not adapted*
- *Very interesting*
- *Well done – sad about the room set up but we made the best of it and the discussion*
- *Very many thanks for all your hard work. It is really appreciated. Great day, thank you again*
- *Room not suitable. Late coffee*
- *Well organised. Good time keeping*
- *Very good. Information clear. Agenda great*
- *Good day. Room with tables would have helped with the discussions but obviously couldn't be facilitated by the centre. Organisers coped well to encourage discussion groups.*
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## Our First AGM

In our first AGM of the ECFS NSiG we voted on our constitution, (also found on our web pages), elected 3 new members to the committee and discussed the way forward. Discussions included how to network in future (e.g. social media, or dedicated forum), how to spend funds, ECFS group membership and suggestions for future conference topics.

## **ECFS Membership and costs**

The discussion about group membership for nurses has been raised with the ECFS following the discussion in Seville and in principle this has been agreed. However we have yet to work out a process for this and will continue to work with Christine Dubois the ECFS secretary. This would require some administration from the ECFS side but it should be feasible as long as we get the names of the nurses associated to one given CF centre and the name of the nurse to benefit from the ECFS Membership at the beginning of each calendar year.

## **Funds**

We have been advised that we have 3000 euros per annum to spend on education. This cannot include travel, or accommodation costs for ECFS members.

Furthermore we have some existing funds left over from the old INSG and we discussed how these should be spent. Suggestions included poster prizes and scholarships.

A small group has been charged to develop this work further to encourage scholarly work and educational grants. This is ongoing and will report at the AGM in Belgrade.

## **Elections and constitution**

We agreed to hold elections for new committee members at the AGM once their 3 year tenure came to an end. The committee members should be representative of the general population of ECFS NSiG members. We voted in three new members in Seville. In June 2018 the Chair and Secretary's tenure will come to an end, so we are seeking to elect 2 new members. Nomination forms have been circulated by e mail to the members and we will vote on the day at the AGM. Silvia Rodrigues Torres has agreed to step into the Chair's role following the AGM.

## **Other activities**

The ECFS NSiG committee members have held six virtual meetings via skype. Activities included evaluation of the Seville meeting, planning for Belgrade and web site development. Kath MacDonald was appointed to the ECFS Education Committee in 2017 but so far this group has seen very little activity. It is expected that they will meet in Belgrade to discuss developments. Kath also has 1 year left on the scientific committee and reviewed over 70 abstracts for this year's nursing and psychosocial posters and case presentations for this year's Belgrade conference.

Ann Raman attended the second Middle East Cystic Fibrosis Conference in Izmir, Turkey in March 2018. Once again she reported that it's surprising how few nurses work in the CF field and there are not many nurses in general in the Middle East. The idea was raised to set up an education program in the Middle East, organised by the Middle East Cystic Fibrosis Association. There is a need to explore what is possible and necessary. The next conference will be held in Istanbul, Turkey.

We were invited to join forces with the Psychologists for a joint study day in Belgrade but elected to keep the status quo this year. We will seek opinion on a joint study day next year at the AGM.