

1ST Annual General Report of the European Cystic Fibrosis Society Nurse Special Interest Group (ECFS NSiG),

To be presented at 1st Annual General Meeting Seville 7th June 2017

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 Special Interest group (ECFS NSiG). The current core committee in 2016 is:

- Ellen Julie Hunstad, RN/CNS/MPH, Oslo, Norway
- Dr Kath MacDonald, RN/Prof.Doc, H&S.Sc., Scotland, UK
- Ann Raman, RN/CNS, Gent, Belgium
- Signe Fog Sønderup RN/CNS, Aarhus, Denmark

The aims of the ECFS 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

Key issues from Basel meeting

1. Education topics for future meetings
2. Potential development of an online forum
3. Individual v's group ECFS membership and costs
4. Development of website
5. Funds and how to spend them
6. Elections and constitution

Basel 2016 (Nursing workshop)



Basel 2016 (Ellen, Ann Kath)



Achievements since Basel 2016:

1. Education

- 73 nurses from all over the world attended the nursing meeting.
- Excellent feedback on programme (Table 1)

Table 1: feedback from Basel meeting 2016

- very interesting, connecting with other countries. We all work very differently.
- enjoyed breaks for networking
- well done good day and program
- this has been a much better meeting, comparing to previous years, much more participative +

<i>dynamic.</i>
<i>- difficult for me to hear, understand and translate everything. But interesting</i>
<i>- I found all presentations informative, some were slightly lost in translation</i>
<i>- it was great to meet colleagues and get experiences from other CF centres.</i>
<i>- very interesting day, workshops brilliant idea to discuss abstract ideas + making people mingle encouraged good networking. Thank you for all your hard work!</i>
<i>- (inter)national guidelines for IV therapy</i>
<i>- poster presentation</i>
<i>- complex case studies</i>
<i>- interdisciplinary collaboration on specific topics in End of Life care, fertilities, adult diagnosis etc. ..</i>
<i>- parent support groups: does every country have them? Are they professionally led?</i>
<i>- what 'school teaching' do other countries carryout? How, when?</i>

Table 2: Ideas for future conferences

<i>- screening</i>
<i>- the role of CF nurses in CF care, advanced nurse roles</i>
<i>- use of social media</i>
<i>- practical topics, workshops</i>
<i>- growing old with CF, living life</i>
<i>- the idea of ECFS nursing forum</i>
<i>- short courses would be a great thing</i>
<i>- mental health (in young adults)</i>
<i>- nurse presenting experiences</i>
<i>- end of life care</i>
<i>- help with networking,</i>
<i>- meet the expert nurse (opportunity to talk with specialist for source topics).</i>

Action: This years nursing conference incorporates social media and end of life care and the formal conference has a “Growing Older with CF” symposium included in the programme.

2. Development of online forum

The group expressed a desire to have a forum for networking and sharing information, ideas and education. We have had a volunteer to take this forward but more work is required on how we do this. We have had discussions with ECFS regarding a forum section on our webpage but this may not be a feasible option. Further options include a Facebook page or Twitter address. We wish to discuss this further at the AGM

Action: Further Discussion at AGM

3. ECFS Membership and costs

The annual 50 euro subscription to ECFS was not popular with all members. This gives free attendance at the Nursing event, a group education budget of 3000 euros per annum and access to the ECFS website. Whilst it was recognized that members were able to attend the pre conference meeting for free, the disadvantage was that many nurses were unable to attend every year, thus they felt paying an annual subscription was of no benefit on the years when

they couldn't attend the conference. Non ECFS members can still attend the conference for a 25 euro fee. Group membership for several nurses in one centre was then suggested.

Action 1: The chair wrote to ECFS to ask for consideration of a group membership.

Response: 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.

Action 2: Seek confirmation and agreement at AGM

4. Update of our webpage

The ECFS have upgraded their whole website and it was imperative for us to update our information on aims and outcomes, membership and constitution to reflect the new group.

Action 1: The committee have updated the information and sent to the ECFS for publication on the new website. At the time of writing however the old information is still in place.

Action 2: The committee have asked for a progress report on our webpage and have been reassured that this is due for completion soon.

5. Funds and how to spend them

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 wish to discuss how these should be spent

Action 1: External speaker booked for ECFS budget for Social media workshop.

Action 2: Discuss at AGM how to spend existing ECFS budget and residual INSG funds.

6. Elections and constitution

At last years meeting we agreed to update the constitution which should be visible on the website soon. Further, 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 ECFS and the general population of ECFS NSiG members.

Action 1: We need to agree on the updated constitution

Action 2: We need to vote on 1 new committee member whose 3 year tenure is at an end.

7. Other activities

The ECFS NSiG committee members have held four virtual meetings via skype to update on: progress with the evaluation of the Basel meeting, planning of the Seville meeting, updating the website and constitution and consideration of ways to develop an online forum. Additionally we have networked with national groups to showcase the work of the committee and seek engagement and support. Kath MacDonald presented an update at the UK annual CFNA event in Birmingham in 2016/2017. She was appointed to the ECFS Scientific committee in 2016 and was able to feedback comments for topics from the Basel nursing meeting into the formal conference programme for Seville. She has reviewed over 90 abstracts for this year's conference. Ellen Julie Hunstad presented update to the Scandinavian CF Nurses Committee at their autumn meeting in Copenhagen 2016 and spring meeting 2017 in Lund.

Ellen Julie Hunstad attended the North American CF Conference 2016 in Orlando, and discussed with committee impressions of nurses presentations, work shops and short courses approved for education.

Ann Raman attended the first ever Middle East Cystic Fibrosis Conference in Oman from Feb 2 to Feb 4, 2017, organised by the Middle East Cystic Fibrosis Association (MECFA).

As a CF nurse specialist, Ann had the opportunity to share her expertise with the attendees. Not many nurses attended this conference, as there are not many CF centres in the Middle East, and especially not many nurses in the CF field. During the 3 days Ann led sessions about all aspects of the disease. Other members present were dieticians and physiotherapists, who also joined her sessions.

Ann reflects:

“It was a tough experience, to hear what difficulties and problems the health care providers and the CF families encounter. But I hope I was able to give them more knowledge and ideas about the complicated approach of CF”.

8. Future Direction

The ECFS continues to progress in scientific and clinical improvements in CF care, and the conference body is growing. The working groups have been important parts of ECFS for many years, and since 2016 Nursing and Pharmacy special interest groups have joined. We expect others will follow.

During the last decade CF nurses have experienced that the opening day of the conference is very busy-with different meetings which involve nurses-happening at the same time. There have been requests for a change to the timing of the nurse meeting to make space for attending different pre conference meetings. The suggestion is to move the nurse meeting from Wednesday to Tuesday. This could be used for continuous development of the nursing educational programme with the introduction of short courses and further development of workshops.

2nd May 2017