

## **5th Annual General Report of the European Cystic Fibrosis Society Nursing Special Interest Group (ECFS NSiG),**

**To be presented at Annual General Meeting in Lyon, France.**

### **Message from the NSIG Chair**

As I write this introduction the hospital I work for is, like for many of you, in the midst of the Covid-19 crisis. I have been redeployed to work in our Intensive Care Unit and my CF patients are shielding at home. Clinic reviews have been converted to video consultations and patients are doing their own spirometry and monitoring at home and relaying the results to us. Despite the anxiety and isolation many are contending with I have been impressed with the resilience that patients have shown in managing their condition and their mental health in the midst of this pandemic. Indeed many seem to prefer the new ways of communicating and keeping in touch that we are using. It is entirely possible that, in the “new normal” we find ourselves after lockdown, that many of these innovations will continue and become part of how we manage patients. Personally I think it encourages independence and self-management although there will always be those patients who need a more “hands-on” approach to ensure good adherence.

Also remarkable has been the revival of a community spirit that has manifested as a result of this crisis. The willingness to help others; to simply be kind has been wonderful to see. I hope that everyone in our CF community has been a recipient of this much-needed generosity at this time.

The NSIG Committee had almost completed the planning for our education and networking day at the 43<sup>rd</sup> ECFS Conference in Lyon. While it was not a surprise to learn it would not go ahead, we were very disappointed. As a committee we are looking to see if any of the content would be suitable to produce as a webinar / virtual conference. We will do our best to produce some material however the great strength of the NSIG day is the discussion and sharing of experiences which is always very enriching. Any thoughts and ideas are always very welcome, so please do not hesitate to get in touch. Also put on hold is the planned elections for new committee members. More of this below, but again, if you are interested in taking up a role in the committee please do not hesitate to get in touch.

I hope you, your family and all your patients are safe and well.

With very best wishes

Nichola MacDuff

## **2019 conference Liverpool. UK.**

The NSIG conference in Liverpool was well attended with over 100 nurses coming together to learn and network together. We had some interesting talks and discussion on a variety of topics including a debate on whether CFTR modulators can be continued during pregnancy. We had our first ever “Innovation of the year” presentations with some very interesting ideas. Harbinder Sunsoa (left) was voted as the very worthy winner.



We also had some wonderful national presentations by specialist nurses from The Netherlands; Portugal and Belgium

## **Website development and update**

All of the presentations from the last 5 conferences can be found on our updated NSIG web pages on the ECFS website and we would encourage members to access this resource. Please also take the time to read the newsletter - the plan is to produce these twice yearly to keep members up to date. Contributions to the newsletter are very welcome – please do so by emailing any member of the committee with your suggestions.

## **ECFS Membership and costs**

### **Funds**

The NSIG have a pot of money that we spend each year on supporting members to get to the conference (the travel award) as well as promoting innovation. New in Lyon was

the “Nurse of the Year” award. Unfortunately this will now have to be delayed until the next conference in 2021.

### **Elections and constitution**

In June 2019 we had elections for the committee as our treasurer, Signe Fog Sønderup had completed her term of office. Annick Lacroix from Belgium was voted in as her replacement. In 2020 there were 3 committee positions becoming vacant. Majda; Yulia and Sylvia have agreed to remain on the committee for a further year given the difficulties in arranging a vote among our nursing members. However, should anyone be interested in becoming part of the committee please contact Angela Roest to discuss coming on board as a deputy.

### **Other activities**

The ECFS NSiG committee members have held 7 virtual meetings via skype. Activities included evaluation of the Liverpool meeting, planning for Lyon and identifying funding for travel bursaries and awards.

The committee also provides representation on a number of ECFS committees: The Scientific Committee; the Standards of Care Committee and the Education Committee.