Paediatric Cystic Fibrosis Newsletter

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The Scottish Paediatric Cystic Fibrosis Managed Clinical Network (MCN) was commissioned by National Service Division (NSD) during 2009 to deliver identified priorities in particular, the provision of equitable care for the clinical management of children and young people with Cystic Fibrosis across Scotland. The aim of the MCN is to support the provision of national standards of evidence based professionally developed and agreed specialist care for children and their families regardless of where they live and regional/local variations in how it is delivered. This will be delivered as locally as possible through the establishment of shared care arrangements between Regional Specialist Centres and District General Hospitals and networked care across regions and pan Scotland where appropriate. The MCN will support the service in improving standards of clinical care through the establishment of continuous improvement systems and process.

Thank you to Nikki Russell, Parent Representative

The PCF MCN would like to thank Nikki Russell for her contribution to the development of the MCN, both before its inception and subsequently as an inaugural member of the Steering Group. It has been invaluable in giving the crucial parent/patient view of how a paediatric CF service should be provided in Scotland. On behalf of the Steering Group we would like to formally thank her and wish her all the best for the future.

Paediatric CF on the Clinical Audit System

The network has been looking at its information requirements in view of the work they have done on developing clinical quality indicators (CQIs) and the Annual Review Protocol. NSD has developed a national clinical audit system (CAS) for all national MCNs and the PCF MCN is looking at how it may benefit the network to use it for the collection of data during the annual review process. For more information please contact Greg. (contact details on Page 4)
Although I am probably well known to many of you there may be some newer members of your paediatric CF teams who have only heard my name mentioned in passing. I was appointed as the first clinical lead in the Scottish Paediatric Cystic Fibrosis Managed Clinical Network in 2009 with my term of office recently extended to May 2012.

The MCN can trace its origins to the West of Scotland in the late 1990’s and since then several of us, under the auspices of the Scottish CF Group, tried to gain national designation for a paediatric CF service network to complement the newborn screening and adult CF services that surround us. Unfortunately national designation was not to be but we were granted funds for a MCN and, together with the parallel National Delivery Plan process of additional staffing for specialist paediatric services, it was hoped that we could still achieve the same aims and objectives that were envisaged all those years ago. After the initial enthusiasm, progress then slowed (due to the lack of network manager for much of 2011) but a momentum has now been re-established such that shared care has been agreed between local clinics and specialist CF centres, which allows more care to be delivered locally and more dialogue between health care professionals. A national annual review guideline has been agreed, with other protocols and guidelines in various stages of development, and a dataset to inform on the clinical quality of paediatric CF services is nearing completion. There are other work-streams being considered, or in progress, and I hope that you will all feel involved and given the chance to contribute to the development of this national MCN for the betterment of our patients through improved clinical outcomes and quality of life.”

Richard Brooker, Consultant Paediatric Respiratory.

“My name is Greg Fearn and I am the new manager for the national Paediatric Cystic Fibrosis Managed Clinical Network. I have been in post since the beginning of October, working closely with Dr Brooker and other members of the network. There are still some of you I haven’t been in contact with yet but I hope to rectify that in the coming weeks. I also manage the Familial Arrhythmia Network Scotland (FANS) and have been doing so since November 2009. I hope to build on the work that Bill Mathieson and others have set in train and also develop new projects which will take the network forward. Initially I am only in post until the end of March 2012 but the situation will be reviewed in the new year. I look forward to supporting the continued progress of the network.”

Greg Fearn, Paediatric Cystic Fibrosis NMCN Manager. Contact number 01382 835183 or 07795 013527, email gregory.fearn@nhs.net.
Network Administrative Assistant

Network administration is provided by Becky Bolger. Becky will be supporting the network for a temporary period of six months until the end of March 2012.

“I was appointed as administrative assistant in October 2011 on a six month secondment from NHS Tayside Payroll department. I’m already three months into my secondment and it has provided me with a knowledge of Cystic Fibrosis and the Network that I would never have been exposed to in my previous role. I am looking forward to attending the next Steering Group meeting and meeting everyone involved.”

Susan Grant, Parent Representative

“My name is Susan Grant and my five year old son is cared for by the Edinburgh CF Team. As many of you will know I am a parent representative for the Managed Clinical Network. Dr Andy Fall invited me to join the group, and I have now attended two meetings. I feel that the Network has an important role to play in improving the standard of care for children with CF. Whilst appreciating that some of the NMCN’s objectives will take time and investment to deliver, I believe there are also a number of improvements which could be implemented in the short-term. I am hopeful that I can bring ideas to the table, based on our family’s experience and, over time, be able to represent other parents in the East of Scotland. I intend to help influence the NMCN to focus on what will really make a difference to the quality of care children with CF receive.

In November, my husband Rich and I attended the CF Trust’s Parents’ Conference in Manchester. This was the first time we had been to one of these events. We found it informative, particularly the slots on gene therapy and the research currently in the pipeline. A few of the web pages referred to were:
- www.cff.org/research/drugdevelopmentpipeline
- www.cfgenetherapy.org.uk
- www.thecochranelibrary.com (select genetic disorder, then CF from the list)

The session run by the clinical psychologist was also useful and generated some interesting discussion, and sharing of ideas, between parents. Also, as many parents we met on the day were with others they had met through their own CF centre, we came home from the conference thinking it would be good to have a network like that locally. I am now working to establish a Parents’ Group in Edinburgh and the East of Scotland, with support from the Edinburgh CF Team and the CF Trust. I am hopeful such a group will have numerous benefits for the parents or carers. In addition, it will better enable me to represent the collective ‘parents’ view which I can channel through the NMCN. Whilst I believe it makes sense to run this at a local level initially, if successful, the model would ideally be rolled out to the West and also North of Scotland.”

Susan Grant, Parent Representative.
Paediatric CF on Facebook

Paediatric Cystic Fibrosis MCN is on the social networking site Facebook. Since the page was launched in August 2010 the response has been good with the number of ‘likes’ increasing such that a shorter, unique web page address has been created: www.facebook.com/paediatricCF.

This page will be updated frequently with up and coming events and useful links and information on Cystic Fibrosis and the Network.

Please feel free to ’Like’ and add comments or links to useful resources.

Annual Review Protocol

The network is in the final stages of developing a nationally agreed Annual Review Protocol to support clinicians when undertaking this crucial aspect of patient care. Annual reviews play an important role in the care of children with cystic fibrosis. This is especially the case due to the potentially complex nature of care involving a wide number of disciplines including among others:

- Medical
- Specialist Nursing
- Physiotherapy
- Dietetics
- Psychology
- Pharmacy

The purpose of the annual review protocol is to ensure high quality management for children with CF on an annual basis. The protocol will be available on the website on completion.

The work has been coordinated via the Steering Group and is due for completion in early 2012.

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www.facebook.com/paediatricCF