Introduction

The aim of the newsletter is to provide an update on the work of the network to the wider community of professionals and support groups involved in the care of families and patients with congenital diaphragmatic hernia. This newsletter will be complimented by the website which will provide access to future publications from the network and relevant links. The website address and contact details for the network can be found at the bottom of this newsletter.

About the network

The SDHCN is a formalised network of professionals working throughout Scotland involved in treating and caring for patients with congenital diaphragmatic hernia and their families. This is being administered by the Managed Clinical Network (MCN) office in Glasgow and is strategically led by a steering group with health professional representation from hospitals throughout Scotland.

The specialties the steering group are drawn from reflect the long-term input needed for managing diaphragmatic hernia, starting from diagnosis, often antenatally, through neonatal intensive care, surgery, and into the long-term with respiratory and developmental follow-up throughout childhood. Mothers-to-be with an antenatal diagnosis of Congenital Diaphragmatic Hernia (CDH) should be offered the most comprehensive and up to date counselling to allow them to plan their pregnancy and delivery in a unit with appropriately experienced clinicians. Though surgery is only undertaken in three specialist paediatric surgical units in Scotland, local teams can provide much of the later care for patients close to their own homes. It is desirable that all health professionals, parents/carers and patients themselves have equitable and evidence based treatment plans. This will be facilitated by a NMCN approach. The SDHCN steering group has a place for patient representation by a parent/lay person. This is vital to ensure the network responds to the needs of the patients and families in Scotland. They will be responsible for canvassing local input into the network.

Message from Network Manager

Welcome to the fourth edition of the SDHCN newsletter, and apologies for the time delay between this version and the previous one. I hope to continue the theme of including any information about the network that the members and the wider community of professionals and support groups involved in the care of families and patients with congenital diaphragmatic hernia will find useful. This will include dates of forthcoming meetings, news of recent events, information on prominent members and useful links for Diaphragmatic Hernia information. The plan is to send this out on a regular basis so that the membership will become accustomed to using it for dates and making sure that the network members are aware of any initiatives or tasks that the sub groups are undertaking. As well as the newsletter being emailed/mailed to you it will be available on the network website that is currently being revamped. The website address and contact details for the network can be found at the bottom of this newsletter. The editorial team will be delighted to receive any submissions for the newsletter and website.

Message from Lead Clinician

Since the last newsletter, the SDHCN has made considerable progress in the development of guidelines and care pathways for antenatal and postnatal management of DH. I am aware from various discussions that these guidelines are used by clinicians in many centres but we remain unclear of the extent of their uptake in clinical practice nationally.

The main deficiency at present is the void created by a lack of robust data to inform and reassure professionals of the clinical credibility of the guidelines we have produced. Creating a registry that is sufficiently detailed to be clinically useful yet streamlined to ensure full engagement has, to date, proven unattainable. Working in conjunction with CDH-UK and other interested parties south of the border, we feel we are closer than ever. In the meantime, the presentation of recent national experiences in this years’ educational meeting will hopefully go some way to benchmark what we have achieved so far.
Current Issues
SDHCN Steering Group
The steering group has had two recent meetings in 2012, one on Sep 3rd 2013 and the latest on 1st April 2014. The next meeting is planned for September/October 2014 at Yorkhill Telemed room where videoconferencing will be available.

Topics discussed at the last two meetings included:
- Sign-off of various standards, guidelines and care pathways developed by the steering group—these have now been placed on our website. This includes the following:-
  Long Term Follow Up Guidelines
  In-Patient Guidelines
  Antenatal Guidelines
  Postnatal Care Pathway
  Antenatal Care Pathway
  Developing an Antenatal Care Record to record Antenatal Management of CDH.
- Development of two patient information leaflets, Antenatal and Postnatal. These have been signed off and placed on the website and distributed to centres across Scotland.
- Development of a clinical audit database. This would allow audit of service performance against evidence based standards to provide a basis for further service improvement. A database has been developed by the network and there are plans to use this as a template for a UK Registry in liaison with the charity CDH-UK.
- Planning of Study Day for 31st October 2014 in Edinburgh. This event will be for professionals only.
- Development of Communication and Engagement Strategy, identifying stakeholders and ways of engagement, i.e. newsletters, website, roadshows.

Subgroups continue to provide a useful forum for sharing information between representatives of professional disciplines across Scotland involved in the care of CDH. We are hoping to be able to include lay representation onto the steering group soon. Leaflets have been distributed and are available from the MCN office inviting enquiries from interested individuals.

Education
The Scottish DH Clinical Network held its third Workshop on 25th September 2013 at the Crowne Plaza in Glasgow.
This was the first UK National CDH Event hosted by the network. The event was held in conjunction with the Fetal Anomaly Screening Programme CDH Workgroup from England and Wales. International speakers attended and the attendance was encouraging with over 60 people, mostly consisting of Paediatric Surgeons, Neonatologists and Nursing Staff. There were also a number of Consultants from other disciplines. Almost 80% indicating the presentations were either “very good” or “excellent.”

Study Day
The SDHCN are planning a study day on Friday 31st October 2014, at the Edinburgh Training and Conference Venue. The morning will include case discussions encompassing antenatal and postnatal management decisions. Further topics will include an update on ECMO, and long-term follow-up.

Current Issues
Website and MKN
One of the key objectives for SDHCN in 2014/2015 is to develop our Communication and Engagement Strategies. This involves three main issues:-
- Identifying key stakeholders, both professional and families.
- Identifying what information they need/want
- Identifying how best to get this information to them

Managed Knowledge Network (MKN)
The Children and Young People’s Services Managed Knowledge Network (MKN) was launched in October 2009 and is hosted through the Knowledge Network (formerly e-library).
The network has developed a Community of Practice Page which has the capacity to include information on:
- Policies, Guidelines & Reports, Education & Events, SDHCN Business & Meetings, Newsletters, Charities & Support Groups and a Contact Us section.
The network also plans to develop this website during 2014/2015
This website will require an Athens password to access. If you have any suggestions on how to populate this site, please get in touch with the MCN department. To access this website click here

SDHCN Website
With regard to communication, the network website remains our main channel for engaging with stakeholders, especially families. The website is currently being revamped and if you have any suggestions please contact the network office.
To access the website click here
Contacts

Current Literature
The editorial team would be delighted to highlight any recent literature relating to Congenital Diaphragmatic Hernia. Please contact the MCN office with any submission

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