

# Newsletter

## Welcome

Welcome to the **first edition** of the newsletter from the North West and North Wales Paediatric Long Term Ventilation Network.

The purpose of this newsletter is to introduce and share information about the Network and the service across the North West and North Wales, as well as update you on relevant learning/ training opportunities and guidelines.

It has been developed primarily to inform and update colleagues in Tertiary Centres and District General Hospital Trusts, community services, PCT's and Service Networks across the North West, North Wales, Isle of Man and neighbouring areas.

Contributors to this issue of the newsletter include Dr Elaine Chan, Diane McKean and Louise Little.

## LTV Equipment Bank

Nationally, it is recognised that there is an increasing number of chronically disabled but (mostly) medically stable children dependent on ventilatory assistance. The North West region oversees one of the largest paediatric LTV populations (outside of London).

Both tertiary paediatric centres are faced with increasing demand of patients needing non-invasive ventilation support semi-urgently with no guarantee of availability of ventilators because of limited supply, which could potentially compromise patient care. There is a need for rationalising equipment supply and maintenance as part of the care package. Currently, within the North West, there is no standard approach towards procurement and maintenance of equipment.

### Network Contact Information

Dr Andrew Selby - Lead Clinician and Chair:  
[andrew.selby@alderhey.nhs.uk](mailto:andrew.selby@alderhey.nhs.uk)

Dr Elaine Chan—Newsletter Editor:  
[elaine.chan@cmft.nhs.uk](mailto:elaine.chan@cmft.nhs.uk)

Suzanne Denley - Network Manager:  
[suzanne.Denley@cmft.nhs.uk](mailto:suzanne.Denley@cmft.nhs.uk)

Louise Little - Network Support:  
[louise.little@cmft.nhs.uk](mailto:louise.little@cmft.nhs.uk)

If you have any articles that you would like to submit for the next issue, August 2012, please contact Louise by 31st June 2012.

### Network Website:

<http://www.networks.nhs.uk/nhs-networks/north-west-and-north-wales-paediatric-long-term>

This issue has been raised and discussed within the North West and North Wales Paediatric LTV Network in the past year, which has led to the circulation of a paper on improving the purchasing of home ventilation equipment, consumables and the maintenance provision (thanks to the hard work and coordination by Roz Jones, Specialised Services Commissioning Manager). We hope that by establishing a centralised equipment bank and streamlining the procurement of equipment, together with provision of a technical support and maintenance service, this will improve the efficiency and safety aspects of the service across the region, treating our patients in an effective and timely fashion. Various options are being considered. This is very much work in progress. So watch this space!

## Tertiary Children's Networks Conference: 6th October 2011

The 2011 North West Tertiary Children's Networks Event was held for the first time at the 'The Centre', Birchwood Park, Warrington. 156 delegates attended on the day in total. Attending were representatives from a wide range of hospital trusts across the North West and North Wales mainly clinical/nursing staff with a limited number from management/commissioning backgrounds. The seminar was opened by and chaired during the morning session by Jenny Scott (Director of Commissioning, North West Specialised Commissioning Team). The delegates were all together for the morning session of the conference and then in the afternoon the delegates divided into five different streams as follows:

- Paediatric Critical Care
- Paediatric Burns
- Cleft Lip and Palate
- Paediatric and Perinatal HIV
- Paediatric Long Term Ventilation

26 delegates attended the Paediatric Long Term Ventilation stream.

During the morning session the delegates were provided with an insight into the different networks, as well as updates on specialised commissioning, the future of trauma, the North West and North Wales Paediatric Transport Service (NWTS) and two educational sessions regarding transition which is of relevance for all the networks. The groups then split

into the different streams for the remainder of the day to focus on the specific disciplines

The afternoon programme for the Paediatric Long Term Ventilation stream included:

- Child, Parent and Carer Perspective
- DVD from a patient and his family shown and his mum was part of the discussions
- Managing Risk in Long Term Ventilation
- The Ideal Care Package: How should we assess what is needed?
- Working with Families and Carers: Setting the Boundaries
- Real Life Examples and Solutions

Feedback on the venue choice and the range of presentations was overall positive.

The evaluation of the event showed that the presentations were well received with all speakers scoring (majority) either "excellent" or "good".

A number of topics have been suggested for future events.

The event was provided 'free of charge' to delegates.

*Thank you for attending and making this a successful day!*



### Morning Session Speakers

*From left:*  
 Jenny Scott,  
 Dr Andrew Selby,  
 Mr Simon van Eeden,  
 Dr Mahil Samuel,  
 Dr Eileen Byrne,  
 Sarah Santo,  
 Dr Andrew Riordan,  
 Fiona Price,  
 Miss Naomi Davis,  
 Miss Mamta Shah and  
 Dr Sarah Gaskell

## Long Term Ventilation Forum 'Drivers for Change', 14th October 2011

The LTV Forum held on 14<sup>th</sup> October 2011 brought together the multidisciplinary health care professionals, social care teams and the families of children on long term ventilation, at Royal Blackburn Hospital. We heard from Gill McKnight, Discharge Coordinator Royal Manchester Children's Hospital regarding the process home. Dr Elaine Chan, Consultant Respiratory Paediatrician, spoke on the conditions and indications for long term ventilation, giving insight into the decision making around when to commence ventilation. Representatives from 2 community teams described their team structure and how they supported staff through training /supervision. We also had the opportunity to hear first-hand from families of children on LTV. Two family members talked about their experience regarding the discharge process, home care package and the difficulties they faced in trying to ensure the best care for their adopted daughter/sister. Pam James, assistant practitioner gave an overview of her experience working in the homes of LTV patients as a carer and now as an assistant practitioner. Pam gave her view on what made a good carer, the difficulties and lessons she learnt to ensure a good working relationship between

the patient/family and their care team. The interview with Ian Stewart, a 21 year old young man who has been on long term ventilation since the age of 6 years offered a personal account of what it felt like to be at the receiving end of the home care from childhood to adulthood, hence the challenges in home care in catering through the ages. He answered honestly with humour, at times with sadness, his fears regarding his care when admitted to hospital where staff did not know him well, his vulnerabilities when staff took short cuts in his care which could jeopardise his health.



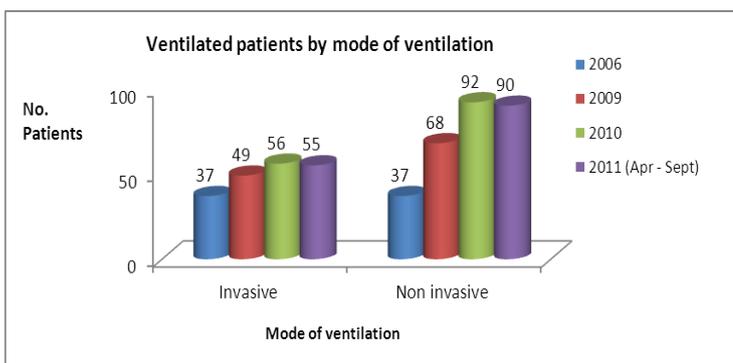
## 'Vital Statistics'

The national survey on children on long term ventilation (LTV) support published in Nov 2010 <sup>1</sup> provided the first census figures for LTV in children in the UK for a decade, since the last survey in 1999. The latest survey collected data on children <17 years of age from 30 regional UK centres totalling 933 children, 22% of which were invasively ventilated via tracheostomy 24 hours/day. There has been a significant rise in the figures compared to the survey conducted in 1999 which identified 141 children requiring long term ventilation in 30 units (in UK), of which 24% were on continuous invasive ventilation <sup>2</sup>. This

trend is similarly mirrored in the NW region (Fig 1). This increase reflects the improvement in technology, growing experience and expertise in paediatric non-invasive ventilation, and changing attitudes towards long term ventilatory support.

### Reference List

1. Wallis, C., et al. "Children on long-term ventilatory support: 10 years of progress." *Arch.Dis.Child* 96.11 (2011): 998-1002.
2. Jardine, E., et al. "Current status of long term ventilation of children in the United Kingdom: questionnaire survey." *BMJ* 318.7179 (1999): 295-99.



**Fig 1** Mode of ventilation undertaken at AHFT and CMFT 2006-2011  
(Taken from the paper titled 'Paediatric Ventilation Services', (16/1/12) author: Roz Jones, Specialised Services Commissioning Manager, NWSCT)