

**Edition 7 June Summer 2010****Welcome to the Seventh Edition of the
North West Perinatal and Paediatric
(NWPPHN) HIV Network Newsletter****NW Perinatal and Paediatric achievements
for 2009 and future network priorities for
2010/11**

The perinatal and paediatric HIV network have had yet another successful year

Key **2009** Achievements include:

- New chair/lead clinician Andrew Riordan, Network manager Andrea Hughes and project support Louise Little
- Small time limited funding until Jan 2011
- Planning and successful delivery of the Sept 2009 network workshop
- Planning and delivery of Parent/carer event in partnership with Barnardos
- Development of Greater Manchester's family centre HIV service at North Manchester General Hospital
- Development of a North West perinatal and paediatric HIV Overview paper
- Development of X2 annual newsletters
- Development of network/service outcome measures

Future priorities for the network for **2010**

- Network workshop planned for the 16th September 2010

- 2010 Annual parent/ carer and children's event
- Transition pathway and protocol work
- Audit to explore what protocols/guidelines are implemented within District General Hospitals for supporting the delivery of infants to known HIV positive mothers.
- To cascade lessons learned and dissemination of good practice guidelines and protocols across NW
- To benchmark services against CHIVA standards
- Exploratory work to be undertaken regarding psychological service support for children with HIV in the NW

**North West perinatal and paediatric HIV
overview paper**

The network has developed a comprehensive overview paper of perinatal and paediatric HIV tertiary services operating in the North West and Staffordshire. The paper aims to provide an overview of service provision, highlight any barriers /risks and to propose a network work programme for 2010/11. The paper will be made available upon request (contact: Louise.Little@nwsct.nhs.uk) once endorsed by the North West Tertiary Children's Strategy Group (June 2010).

**North West Perinatal and Paediatric HIV
Network Review of local hospital
guidelines for management of Infants
Born to HIV Positive Women (2010)**

All North West and Staffordshire/Shropshire District General Hospitals lead Neonatal or Paediatric consultants (in particular those hospitals who have delivered HIV positive children within the last 2-3 years) should

have received a letter detailing the work being undertaken by the NW perinatal and paediatric HIV network regarding reviewing NW guidelines and protocols for delivering infants to HIV positive women. This is an important audit to ascertain what guidelines are currently being used, if any, and whether they meet the 2009 CHIVA recommended Standards of Care. Once the results have been aggregated, clear guidelines /protocols will be disseminated to all trusts along with a letter detailing lessons learned and support/advice on offer.

Once the audit is complete, findings will be presented at the Sept 16th 2010 annual network workshop.

Date for your diary!
2010 NW Perinatal and Paediatric annual network workshop:
16th September 2010
Village Hotel, Warrington

Snapshot of Programme:

- Network achievements and future work priorities
- Young people's experiences (Video)- Barnardos
- Mother to child transmission
- Management of HIV positive pregnant women
- Neonatal Management
- CHIVA updates
- Lively afternoon debate

North Manchester General Hospital HIV family Centred Services Update

The establishment of the family centred HIV service based in North Manchester General Hospital is making excellent progress. A Paediatric Dietician, Physiotherapist, Pharmacist, Play therapist and Phlebotomist have been internally recruited and have already joined the Multidisciplinary Team. The Paediatric Clinical Nurse Specialist Post (Band 7) has been recently advertised and will bring a welcomed addition to the Paediatric HIV service within Greater Manchester. The Paediatric Infectious Disease Consultant Job Plan is currently awaiting Royal College Approval and will be advertised thereafter. Toni Tan is currently meeting with the Clinical Lead of Clinical Psychology of Manchester to discuss the arrangement for a contribution to the Family Clinic.

CHIVA (Children's HIV Association) Standards of Care for Infants, Children, and Young People with HIV, (including infants born to mothers with HIV)

Final CHIVA Standards (2009) can be sourced at:

<http://www.chiva.org.uk/health/guidelines/standards>

North West perinatal and paediatric HIV network website presence

The NWPPHN now has an exciting website presence within the CHIVA website. Please visit us at

<http://www.chiva.org.uk/networks/northwest>

Network 2009 Consultation Event

The 2009 Network Consultation Event took place at George House Trust, Manchester on 13th November. The event, organised by the children & young people's HIV Social Work Team based at Barnardo's Gregory's Place, brought together seventeen parents/carers of children living with HIV with a similar number of workers from medical/support teams from across the North West.

The following provides a brief overview of the different sessions that took place throughout the morning;

- **Session 1** presentations from four parents who talked about their experiences of caring for children who live with HIV. The audience heard about both emotional & practical aspects of parenting a child living with HIV & also about the good practice examples that parents have experienced from clinics & from social support services which have helped them (& their children) to come to terms with a childhood HIV diagnosis.
- **Session 2** introduced round table discussions which allowed 6 groups to agree & outline important issues for both parents/carers & workers to consider when providing pre-disclosure support, the naming of HIV & post-disclosure support to children. Key themes included confidentiality, age-appropriate information & on-going, continued support.
- **Session 3** was a panel of medical staff who answered parent/carer questions specific to children/young people living with HIV. This is a

popular session that is becoming a regular at the Consultation Events!

The morning finished with a shared lunch & the chance to talk informally with each other in a comfortable & friendly environment.

The Evaluation forms received were really positive & it seemed that all those who attended were able to get a lot out of the event.

BHIVA and CHIVA Conferences 2010



May 28th 4th CHIVA Annual Conference Brighton Dome.

The theme was “Back to Basics” and to start the conference one of the CHIVA Youth Committee opened the day with a presentation of a study on peer support. We had other poster presentations, followed by Professor Saye Khoo on pharmacokinetics and therapeutic drug monitoring. The traditional debate this year was: “Antiretrovirals should be started in all HIV positive children immediately to protect the child’s brain”: which was an entertaining and close fought battle seeing a swing in favour of the motion.

The next session was on Research and Audit: with an update on the National Study of HIV in Pregnancy and in Childhood by Pat Tookey; results of the CHINN audit from Clare Foreman; and Professor Di Gibb on “Towards availability, sustainability and acceptability of ART for children and young people”.

In the afternoon nurses and voluntary sector from each of the regional networks gave updates about their activities

In the final session a minister from the Midlands delivered an excellent presentation on Faith – friend or foe. Finally the young people talked about CHIVA Projects: CHIVA website, Youth Committee and Summer Camp.

October 8th CHIVA Parallel session at BHIVA Conference London

Transition is the theme for the conference this year. We will start with the plenary session with BHIVA delivered by Jose Tomas Ramos Amador from Madrid on transition practice in Spain.

The next session is on Research and an Adherence Audit. This will be followed by examples of problems with Transition in other medical conditions.

In the 3rd session we will learn from the experience from transition clinics: Sexual health (Mortimer Market clinic); Motivational interviewing (St Mary’s 900 clinic); Pregnancy Audit (St George’s); ARV choices for young people (Birmingham); and Moving hospitals from a smaller unit.

The final session will bring together CHIVA Policy on Transition with Adherence strategies in Madrid; Voluntary sector and General Practice role in Transition and finally a summary of policies for transition.

For more information on the CHIVA conference: see www.CHIVA.org.uk

CHIVA Summer Camp 16th–20th Aug 2010

100 places for children/young people (13-17 years) living with HIV. To register a child/ young person please go to www.chiva.org.uk

HOW TO MAKE CONTACT.

Please contact Andrea Hughes (NW Children’s Programme Manager) for enquiries regarding the NW Perinatal and Paediatric HIV Network:

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