



**NIHR GREATER MANCHESTER,  
LANCASHIRE & SOUTH CUMBRIA  
MEDICINES FOR CHILDREN  
RESEARCH NETWORK**

**National Institute for  
Health Research**



# NETWORK UPDATE

Welcome to the **Greater Manchester, Lancashire and South Cumbria Medicines for Children Research Network (GMLC)** newsletter.

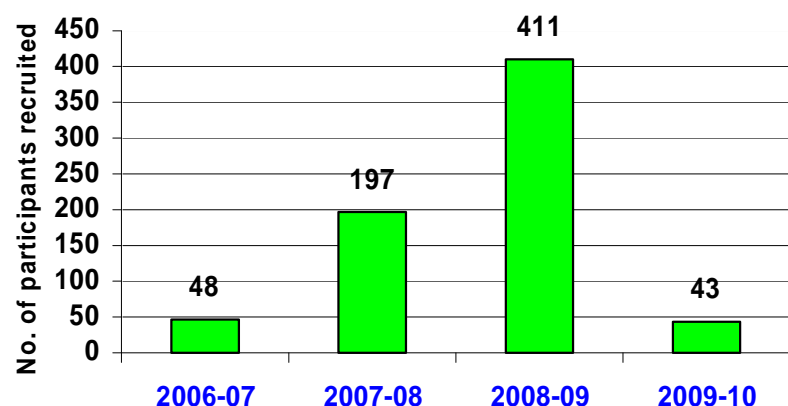
## NETWORK ENDS 2008/09 YEAR ON A HIGH!

The network continues to help build capacity for paediatric research across our region, and the 2008-09 reporting year highlighted many successes:

- Recruitment doubled to 411 participants compared to the previous years total of 197 (see below)
- Our highest recruiting studies were: Nephropathy Familial Study – 84 participants; Lysosomal storage disorder – 65 participants; DEPICTED – 51 participants; TIPIT – 35 participants; Information Matters Project – 26 participants
- Our highest recruiting sites were: Royal Manchester Children's Hospital – 180 participants; Stepping Hill Hospital – 73 participants; St Mary's Hospital – 48 participants; Booth Hall Hospital – 37 participants; Royal Blackburn Hospital – 26 participants. Our second and fifth highest recruiters were district general hospitals.
- MCRN studies are running at 22 separate NHS sites within the network
- 73% of our studies are non-commercially sponsored and 61% are clinical trials, with 43% of recruitment into randomised controlled clinical trials

These achievements wouldn't have been possible without the dedication and support from all our partners. Thank you all!

Our growth remains steady, and we hope to surpass these achievements during 2009/10, as we will have a brand new Children's Hospital and many of our district general hospitals will be coming "online" with their research.



**CALL FOR FLEXIBILITY & SUSTAINABILITY FUNDING (FSF) APPLICATIONS**

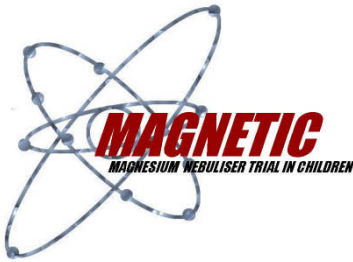
**FSF can be used to fund staff time for up to 1 year - visit our website for details on how to apply**

## STUDY NEWS

Full details of our study portfolio can be viewed at: <http://www.gmlc-mcrn.org.uk/index.php?id=48> with a link to the NIHR portfolio also available here.

### Neonatology

**TIPIT** has now closed to recruitment well ahead of schedule. All our sites recruited babies and a long term follow up study is planned. **ADEPT** has now also reached target with assistance from the MCRN and **PUPS** will shortly open in Salford and Stepping Hill. We also will be working with neonatologists to develop capacity in our neonatal units for commercial pharmacokinetic studies and a meeting on this subject is planned for September, details to follow.



### Respiratory

**MAGNETIC** has now opened at 4 of our sites with patients recruited at Wigan and Tameside. **MASCOT** has finally opened, however, recruitment is slow via primary care and we are now working within secondary care to identify eligible asthmatic children. We also have 2 new studies focusing on children with asthma on steroids. The **EMSC** study is due to open shortly at 2 sites and will be looking at using salivary cortisol as a less invasive measure of adrenal reserve. The

**PASS** project is interested in the pharmacogenomics of adrenal suppression and will run in parallel at these sites, and also alone at East Lancashire and possibly Tameside. We are still seeking sites for both studies, so get in touch if interested.

### Endocrinology & diabetes

Our growth portfolio (**METABOLOME, Commercial SGA study and Growth Hormone Quality of Life**) is led through the tertiary centre, with crucial involvement from many District General Hospital sites who help identify eligible patients.

On the diabetes front, **NFS** has recruited >80 children across 4 sites, of which some will be eligible for the **AdDIT** trial looking at the best treatment for the prevention of long term complications in type 1 diabetes. **KICK OFF** has been adopted recently and will be opening at several sites and will focus on improving the compliance of children with their treatments. **DETEMIR** is now open at Bolton and Stepping Hill and will be enrolling adolescent girls to investigate weight gain in 2 types of insulin. The **MOCA** trial is near completion, but is still seeking referrals for children with abnormal glucose levels and obesity (contact us for details).



### Neurology

**MENDS** continues to recruit strongly and a 2nd site is now open in Blackpool to cover our northern region. The **ICISS** trial is now open at most network hospitals, with several patients enrolled already. We are also working with the tertiary centre team in setting up a new migraine study called **P3MC** which will be seeking referrals from other local hospitals. Our sites are also likely to be involved with a number commercial studies in this specialty, particularly epilepsy.

### Renal

Our Deputy Director Dr Nick Webb continues to drive the renal portfolio having successfully completed several studies and with new ones on the horizon: **RaDaR; MYCYC** plus several commercials including a hypertension study involving losartan.

### Metabolic

The Willink team are world class at recruiting into metabolic studies. We are very pleased that they now have a variety of studies MCRN adopted (**LSD**; 2 commercial MPS IV studies), with more in the pipeline as they persuade more companies to utilize the MCRN.



## NEW NURSES START IN OUR NORTHERN REGION

Our new “northern” nurses (funded by the Cumbria & Lancashire Comprehensive Local Research Network) have now started, and will be leading our expansion of paediatric activity at NHS sites within Lancashire and Cumbria.

Both nurses are paediatric trained and Mel Farman (pictured top left) joins us from school nursing, having also spent time at East Lancashire Trust and will be working part time. Jacqui Woods (bottom left) will be full time and comes to us from Blackpool A&E and is currently studying for a Masters.



Our “northern team” will be based in the paediatric department of the Royal Preston Hospital, and between them, they will provide support to all key sites of the 4 hospital Trusts in the area. Although they will initially focus on secondary care, they will also be engaging with primary care and mental health services as the portfolio develops locally.

We are also very pleased to announce that network funded local paediatric nurses are now in place at Blackpool (Jackie Bradley) and Preston (Sue Kerfoot), with plans underways for posts at East Lancashire and Morecambe Bay.

If you would like to meet or speak to Mel or Jacqui, then please get in touch with them at: [melanie.farman@lthtr.nhs.uk](mailto:melanie.farman@lthtr.nhs.uk) and [jacqueline.woods@lthtr.nhs.uk](mailto:jacqueline.woods@lthtr.nhs.uk)

## DEVELOPING CAPACITY FOR INDUSTRY STUDIES IN THE NW

One of the priorities of the networks is helping support industry led studies (i.e. funded by pharmaceutical companies) within the NHS. 15 years ago, the UK was highly successful in drug discovery and trial conduct, however, in recent times the NHS has become a bureaucratic and expensive place to conduct research, and companies are moving their business elsewhere. This reduction may not seem important, but it means NHS patients do not have access to studies of novel drugs, and the NHS is losing money (industry spends >£4 billion/annum on UK R&D) which has historically been used to support our important academic research.

In paediatrics, co-operation with industry is vital, as recruiting more children into their studies will result in more products licensed for the young more quickly, as frighteningly ~50% of drugs used in hospitals are not licensed for children, rising to 90% in neonates. The MCRN has been at the forefront of this relationship and the UK is now considered to be one of the best countries in the world to develop and conduct research in children.

So what does this mean locally? In order to place studies in the UK, industry want to be satisfied a site can deliver and will conduct a “feasibility” first. Traditionally, companies have always approached tertiary centres, but with saturation in some specialties, it is critical that we involve other sites. Feasibilities often demand a quick turn around, and we send out our feasibilities via our Research Leads and also directly to relevant clinicians. We are very keen to involve more sites in commercial studies, so if you receive a feasibility, then please discuss it with us if you haven’t been involved in an industry study before, as we can help you to determine if you have the patients, facilities and support to deliver it successfully (network nurses may be able to assist with recruitment). More information is available from our website in the downloads section.

We are also likely to be part of a Department of Health project using the NW as a pilot for proving to industry that the NHS can deliver studies to time and target. We will provide more details in the coming weeks, but all of our industry studies will be under the spotlight for the next year!

## TRAINING AND EVENTS

Our conference will be held on the afternoon of 10th July in Bolton, visit our website for details. Our Good Clinical Practice training days continue to be popular, and a programme of GCP events for 2009 and other local research courses can be found at: <http://www.gmlc-mcrn.org.uk/index.php?id=8>. Other courses can also be found at the NIHR CRN website (<http://www.ukcrn.org.uk/index/training.html>) for researchers working on NIHR studies.

## MANCHESTER DIABETES RESEARCH EVENT

The first ever Manchester Diabetes Research Day was held at Old Trafford cricket ground on 25<sup>th</sup> February, with over 130 members of the public attending the event. Co-hosted by the Greater Manchester, Lancashire and South Cumbria Medicines for Children Research Network and the North West Local Diabetes Research Network, the event gave people and parents of children with both type 1 and type 2 diabetes, a chance to find out about research into new treatments.



Dr Rakesh Amin, Consultant Paediatrician at the Royal Manchester Children's Hospital presented about diabetes research in children and along with Dr Chris Cooper (pictured above), Consultant Paediatrician at Stepping Hill Hospital and Sue Greenhalgh, a paediatric Diabetes Specialist Nurse, he also hosted a question and session for families affected by diabetes. Sarah Rickard, GMLC Manager, said: "The feedback we've had has been excellent, with attendees calling the question and answer session 'very good' and the presentation 'very informative'. We hope to run more events in future and continue to engage with parents and children affected by diabetes."

## COMMUNITY ENGAGEMENT WEEK

The week of 30th March-3rd April was the Central Manchester University Hospitals NHS Foundation Trust's Community Engagement Week. The event gave members of the public and staff an opportunity to come and see what each hospital department does, and included a wide range of services from catering to surgery. Thursday 2nd April was dedicated to the Children's Division, with stalls representing many areas of children's care including therapeutic and specialised play, speech and language therapy, radiology and pharmacy.



*Members of the GMLC team on our stall*

The children's day attracted the highest number of attendees of the week, with a large number coming from local schools. The focus of the day was around getting the children involved, and they were encouraged to learn about each area by finding the answers to quiz questions by reading the materials and asking questions at each stall. The children and young people had a chance to test their knowledge of research at our stall by playing our 'true or false' and 'medicines game', and the goodies that were handed out (including teddies and yoyos) disappeared faster than the leaflets!

These recent events have allowed us to engage with patients, families and the public about research. We will be doing much more work in this area when our new User Involvement Co-ordinator begins with us shortly.

## WE HAVE MOVED!!!

**Greater Manchester, Lancashire & South Cumbria  
Medicines for Children Research Network**

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