

Present:

Kathy Bailey, George Eliot Hospital - Chair
Clive Ryder, Birmingham Children's Hospital - Vice Chair
Annabel Copeman – New Cross
Pam Whitworth, Birmingham Children's Hospital
Julia Greensall, Partners in Paediatrics

Apologies:

Jon Packham, University Hospital of North Staffordshire
Ruth Upton, Parent Representative
Richard Brough, Shrewsbury Hospital
Helen Duffy, University Hospital of North Staffordshire
Karen Davies – New Cross (Maternity Leave)

2 Matters Arising

- **Corporate presentation:**
- Regular teaching on regional training programmes has been established for A&E (Annabel), general practice (Clive). Orthopaedics is yet to be confirmed (Clive). Paediatrics has an established slot for both SHO and registrar training. Local training continues to all specialties in addition to this.
- **PIP Website:** The Rheumatology section has been updated. It was agreed that it would be good to have links from other websites – i.e. BSPAR, CCAA, Dream team, local trust websites – to the PIP website in the future.

Action: Kathy to explore this.

- **Questionnaire:** Julia to ascertain how many responses to this Questionnaire have been received and to link with Pam Whitworth to collate the results. (Following Janine's departure from BCH, it is necessary to find another physio to attend the Network Meetings – Rosanne Wilshaw, based at BCH, was suggested and will be approached).

Action: Pam to speak to Rosanne.

- **Meeting with South Birmingham PCT:** The scheduled meeting in January had been cancelled. However, the PCT is now agreeing requests for funding.

3 Feedback from Meeting with Jonathan Howell – 25.04.08

Clive and Julia had had a useful meeting with Jonathan prior to the Network meeting.

Issues discussed:

- a) Progressing the Business Case for the Network and getting it on the agenda for local commissioners;
- b) The complexity of getting the funding approved for some new drugs (often expensive).

Clive pointed out that there are currently 9 different mechanisms for patients getting drugs, across the West Midlands. The process of getting agreement from Commissioners to start

patients on drugs is often a complex, time-consuming and frustrating process for the clinicians concerned. There is a big problem with those drugs where there is no NICE guidance. However, it also applies to the drug Etanercept - for which there is NICE guidance. In Warwick, the view is taken that drugs are new developments, and can only be presented once a year for consideration.

It was agreed that the best way to progress things is through the Local Collaborative Commissioning Boards (LCCBs), although it may not be possible to get one PCT to speak for all PCTs. As a first step, a business case will be developed which can be taken first through the PiP Steering Group, and then through to the LCCBs.

Julia said that, following a letter which had been sent out by the PiP Chair, Stuart Poyner, requesting additional funding to support the Network, 3 PCTs had responded positively. There is now an additional £15k to spend on supporting the work of the Network Group.

There was considerable discussion about looking at 'New ways of Working' and exploring new or extended roles that nurses could take on in the future. This is particularly important when the implications of the Working Time Directive 2009 on Junior doctors working come into force. There are going to be monies available through the West Midlands Deanery, so it would be good to be able to put together a proposal for specialist training of nurses within the Network.

Actions:

- A Business Case will be developed for presentation to the next PiP Steering Group meeting (scheduled for 9th July).

The 'ideal' model of care needs to be agreed. Clive will prepare 3 templates of care as examples – from total centralised care, to local care in DGHs. It is acknowledged that no clinicians are working in total isolation, but the particular problems of single-handed practitioners could be resolved with a Network model of care. (These can be discussed further at the BSPAR Executive on 4th June). The model of care would need to be agreed with representatives from all the Units providing rheumatology services. With the development of business plan, roles/responsibilities and competencies required within the network also need to be considered. Issues around training, maintaining skills and teaching of other professionals who refer to the service, also to be included.

- Jonathan is taking a discussion paper, regarding the introduction of new technologies, to the LCCB in 2 weeks' time.
- The Group needs to decide how the £15k can best be spent. Some ideas proposed were: to buy in additional support to do the 'costings' for the business case; further workshops / events for parents / young people themselves; contribution towards the making of a DVD; supporting the development of the CCAA website (which would benefit all families with children / young people with rheumatological problems).
- The Group to consider preparing a Bid for increased training of Rheumatology nurses across the Network.

3 Draft report from parent's day – for discussion

Julia had circulated a draft report from the Parent's day in November 07.

Action:

- Comments / amendments be forwarded to Julia at the earliest opportunity, so that this can be circulated to those people who had attended.
- Actions from parents work groups
 - Video from parents expressing their views about service development and needs of their children
 - Flow chart to be given with info at diagnosis so know what to expect – and when
 - Explore CCAA website to allow parents to communicate
 - Explore how to achieve equality of funding and access to drugs

Kathy had done some initial work on a Flow Chart. This had been a proposal made by parents at the event in November. All members agreed that, with further amendments, this would be an extremely useful tool. It could possibly be given alongside the 'CHAT' publication, and another page could be added for General Practice to explain about biologics. It could also be used to supplement presentations / lectures.

Julia updated that the CCAA website has had a major improvement and may be offering support in the way requested by parents.

MCRN have advertised for a parent representative. The invitation has been forwarded to all our parent contacts.

Actions:

- Kathy to do further letter to those parents who had responded, to update them on progress including MCRN, business case and CCAA website
- Kathy to make amendments to the Flow Chart.
- Pam to telephone some of the patients to try and encourage more involvement.
- Clive to contact parent of child with a recent diagnosis of JIA to see if they can assist with the production of a DVD. The parent has media connections.

3a Response from families to letter from Kathy Bailey

Kathy had e-mailed or posted a letter to the parents who had attended one (or both) of the 2 Parents' Days, explaining that MCRN were interested in working with the group to understand parents needs to support development of care and work that could be done for the network. She had received several replies. It is thought that there are advantages to linking the parental involvement work with the MCRN, as they have resources and facilitators who want to work with families concerning the provision of drugs.

It was noted that the MCRN formulations group in Warwick are doing work around patients' attitudes to drugs. A bid has gone in for funding for a project to look at what patients and parents think of medications, how many doses are being missed, what is being crushed and what it is mixed with etc, in order to identify areas for development.

3b Confirm date for next parents day

The date of the next Parents day will be Saturday, 15th November. The venue to be George Eliot Hospital (GEH).

3c Suggestions for programme

Some ideas were discussed:

The morning session: cover some of the important issues that parents with children with newly diagnosed JIA need to know.

The afternoon session to cover new topics:

- MCRN could be asked to talk about the work the group is doing on research into drugs / issues concerning licensing of drugs;
- Adult rheumatologist could talk about the adult perspective of JIA when the young person has moved on.
- Update on developments with drugs.

It was agreed, following feedback, that young people will not be involved in this meeting, but that a separate event will be organised for them. Network to support events arranged by BCH to allow young people from the region to attend. To be discussed further with team at BCH.

4 National Network Links – CSIP

It was noted that the Department of Health and the SHAs have implemented changes to the way the Care Services Improvement Partnership (CSIP) works. These came into effect from 1st April 2008.

There are now four national improvement programmes within CSIP, one of which is 'Children & Families'. The Programme Lead for this within the West Midlands is David Allan.

Although CSIP is one of the agencies which supports the implementation of Local Involvement Networks (LINKs), these appear to more Local Authority than Health Networks.

The lead for progressing Networks appears to be with the National Centre for Involvement (NCI).

Action: Julia to contact David Allan, to see if he can support the work of the Network in any way, and to clarify the help that the NCI can offer the Network.

6 Areas for priority for 2008 / programme of work

The development of the Business Case, and the ongoing work with parents and young people, will be the main areas for work during 2008.

Standards of Care

When developing the Business case, the BSPAR standards of care need to be included. It was recognised that, if there are Standards of care, these should be audited.

Audit

It was agreed to carry out a prospective audit of new patients – from the point of referral. Evaluation of MTX against RCN guidance

Action: Kathy to prepare a proforma to be used for this audit. When completed, the proforma will be circulated. Each clinician to audit the first 5 new patients seen on an annual basis.

Pam to look at developing simple questionnaire for parents re: MTX

Peer Review

This is an important area of work that the doctors wish to progress. There was considerable discussion about the things that are important to cover, and the issues that need to be covered for it to be a valid process. It was agreed to review the last 6 patients, with any diagnosis, at the next CPD meeting.

Actions: Kathy agreed to present the first case for this at the meeting on 30th July.

Annabel to investigate any guidance available on peer review.

7 AOB

Terms of Reference: These were considered (as reviewed annually) and some minor amendments made.

BSPAR:

As from October 2008, Clive will be the convenor for BSPAR.

A network group is being established within BSPAR; the purpose of this group needs clarifying. Suggestion; identify the needs of networks to be addressed by other areas such as clinical affairs with Standards. Also to further develop peer review and evaluation of services, and ensure all services are part of a network.

8 Date and Time of Next Steering Group and CPD Meetings:

2008 Steering Group meetings: all held from 10 am – 12.30 pm

Friday, 11th July – **please note this meeting will be held at GEH**

Friday, 24th October – Venue tbc

Friday, 16th January 2009 – Venue tbc

Medical Subgroup meetings

12 June – tbc to further develop network models for business plan

Other Sub group meetings tba

CPD meetings :

30 April SLE and Antiphospholipid antibodies with Caroline Gordon - BCH (3pm) |

30 July CPD and Case Review – KB - George Eliot Hospital

Dec 17 with Christmas night out