

**Present:**

Kathy Bailey, George Eliot Hospital - Chair  
Clive Ryder, Birmingham Children's Hospital (Vice Chair)  
Dr J Packham, University Hospital of North Staffordshire  
Dr Karen Davies, New Cross Hospital  
Janine Hackett - Birmingham Children's Hospital  
Julia Greensall, Partners in Paediatrics

**Apologies:**

Ruth Upton, Parent Representative  
Pam Whitworth, Birmingham Children's Hospital  
Richard Brough, Shrewsbury Hospital  
Annabel Copeman – New Cross  
Alex Tabor, UHNS

**2 Matters Arising**

- **Corporate presentation:** Clive to send copy to all
  - **NHS Networks:** The Rheumatology Group is now on this website. NB: This can be accessed on the URL: **[www.networks.nhs.uk/networks/page/1106](http://www.networks.nhs.uk/networks/page/1106)**
  - **PIP Website:** The info relating to the Group has been updated – more work is needed on the PIP website generally
  - **Questionnaire:** This has been circulated to Heads of Physio depts in Acute trusts; however, it also needs to be sent to PCT Heads of Physio. Copy to be sent to Jon Packham to forward to the Physio in the PCT.  
**Actions:** Julia & Janine. Aim to complete this work by mid-February.  
Send copy of questionnaire to all consultants to forward to local contacts
  - **Links with Pharmacy Consortium:** Clive explained that there have been directorate management changes at BCH; also the BCH Pharmacy dept are currently 'dismantling' the Home Delivery Services and do not want to centralise services (for the distribution of Methotrexate); Kathy said that some progress about this issue is being made in Warwick.  
**Action:** Clive is talking to a commissioner at South Birmingham PCT on 22.01.08 and it is hoped to be able to progress things with him.  
Kathy and Jon to also speak to respective PCTs about the advantages of centralising the service.  
There is also the potential for working with Stoke PCT, as they are currently separating into Provider / Purchaser arms.
- E-mail from Jonathan Howell (dated 14<sup>th</sup> November) with proforma for commissioning new drugs to be forwarded again to Kathy and Clive.
  - **Action:** Julia

### **3 Feedback from PiP Steering Group meeting on 24.10.07**

Clive had attended this meeting and reported on the important issues facing the work of the Network Group. Over recent years, the way patients with rheumatological problems are treated has changed considerably, particularly with the availability of a number of drugs - although often expensive.

Clinicians have to spend a considerable amount of time discussing the needs of individual patients, with different PCTs, in order to get agreement for these drugs to be used.

At the meeting, the PiP Chair had agreed to discuss with his fellow PCT CEOs, the proposal to set up an appropriate Forum whereby drug issues could be discussed and dealt with collectively on a 'timely' basis.

#### **Actions:**

- In order to assist this process, Clive to prepare a one-page document, outlining the problems recently experienced concerning one patient with uveitis – where there was a considerable delay in getting approval for the drug Infliximab.
- Clive and Julia to meet with Jonathan Howell in the near future to discuss this further.
- Ensure paediatric rheumatology on agenda of any local network boards for paediatrics.

### **4 Feedback from Second parent's day – 10<sup>th</sup> November 07**

This event had been successful and evaluated extremely well.

#### **Action:**

- Julia to forward the main points arising from the event and action points from group sessions. A short report to be prepared and circulated to all participants.
- Clive and Bernie's talk to be emailed to Julia

### **5 Parent involvement / user involvement**

Kathy explained that she is involved in the work of the Medicines for Children Research Network (MCRN). MCRN have facilitators who want to involve users, particularly children and young people themselves, in supporting their work research and development of medicines for children & adolescents with rheumatological conditions.

It was agreed that this was invaluable work and would support the work of the Network group.

**Action:** Kathy to write to all those families who have attended the last two education days and inform them of this initiative.

## 6 Ongoing work at present

Therapy questionnaire.

There was discussion about the fact that many therapists in DGHs do not attend training events due to service commitments.

There is a National Therapy Managers' Group – and the Band A Physio at BCH, Janice Scott, has asked to attend this meeting and present a case to the National Forum.

It is understood that the West Midlands Deanary may have surplus money available for training.

**Agreed:** The results of the therapy questionnaire could feed into the National Group and business case.

### Standards of Care

KD finalising draft for standards of care with input from BSPAR  
BSPAR standards to be adopted locally

## 5 Areas for priority for 2008 / programme of work

There was not enough time at the meeting to discuss all the issues in depth.

### Audits:

Produce Therapy standards (BSPAR standards) and audit against these  
Audit standards for MTX, Joint injections, ophthalmology referral and FU

### Peer review

Review last 6 JIA patients at CPD meeting  
Each centre to present once every 3 years  
Develop proforma

### Action: KB

Develop proforma for audits and Peer review  
Add to agenda for CPD meetings  
Produce rota for who will present

## 6 National Network Links – CSIP

Not discussed – to be put on the agenda for next meeting.

## 7 Any other business

- Janine is leaving BCH to take up a lecturer post in Derby – We all wish her all the best!  
A replacement is needed for her place on Steering Committee. Janis Scott to attend in interim.

- Julia asked if group would be interested in hosting a study day for professionals involved with children with arthritis.

**Agreed:** This would be considered at some point in future

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

### **2008 Steering Group meetings: all held from 10 am – 12.30 pm at Stafford PGMC**

Friday, 25<sup>th</sup> April

Friday, 11<sup>th</sup> July

Friday, 24<sup>th</sup> October

Friday, 16<sup>th</sup> January 2009

### **Medical Subgroup meetings**

Attach to steering group/CPD meetings for convenience

Other Sub group meetings      tba

### **CPD meetings : 20<sup>th</sup> February**

19 March

Uveitits with John Ainsworth

BCH

30 April

SLE and Antiphospholipid antibodies with Caroline Gordon

BCH (3pm)

30 July

CPD and Case Review – KB

George Eliot

Dec 17 with Christmas night out