



**Monday 27<sup>th</sup> April 2009**

**Present**

Neil, Nigel, Alistair, Tracey, Steve, Jo, Sue, Mark, Sarah, Debbie & John

**Apologies**

Viv & Toni

This meeting was an opportunity for the group to discuss paediatric diabetes care in Milton Keynes with Dr Nick Hicks Chief Executive and Director of Public Health for the Milton Keynes Primary Care Trust and Director of Public Health for Milton Keynes Council.

Neil welcomed Dr Hicks and explained that the MK Kids group has been in existence for 6½ years & that their main concerns are;

- 1) The provision of a full range of paediatric diabetes services by Milton Keynes Hospital
- 2) That they don't have open lines of communication with the hospital & yet they represent approximately half of the families in this area.
- 3) Education on diabetes care is poor in that post diagnosis there is no regular education on offer to families, the quality of the information given to schools is lacking & there is not a Local Authority policy regarding diabetes care in schools.

Dr Hicks

- Thanked the group for its willingness to help develop and improve the diabetes care currently on offer to children under the care of Milton Keynes Hospital. From the commissioning side of things this type of local involvement is what the PCT is keen to develop.
- Confirmed that 6 weeks ago the PCT were finally invoiced for the provision of a 2<sup>nd</sup> PDSN – Jackie. He expressed his frustration with how long it had taken the hospital to advertise & fill this post, but believes her appointment is a step in the right direction.
- Stated that in commissioning Milton Keynes Hospital to provide paediatric diabetes services for this area, the PCT's expectation of the contract is that

the minimum care the hospital should offer is the level of service identified in the NICE guidelines.

- Asked the group for examples of where they feel the hospital is failing our children.

*The parents / group members present;*

*Expressed concern about the initial education given to families – several examples given, which covered over three years in time, of families not being educated on ‘sick day rules’ at diagnosis & children then being readmitted to MK hospital with sickness and diarrhoea bugs before this education has been given.*

*Frustration at the limited contact parents have with the part-time PDSN at the hospital – telephone answer machine only, any chance of improving this to an e-mail service? In a local resolution meeting it came to light that the hospital is in the process of obtaining costings for a multi-hospital/regional 24 hour telephone service but what stage has this reached?*

*Alistair commented on the reluctance of MK hospital to embrace new regimes (mdi, insulin pumps etc) and offer information on them willingly – general agreement of parents present that new information / ideas are only discussed when brought up by parents themselves.*

*Incidentally - some newly diagnosed parents have been told there is no budget available for more children to have insulin pumps.*

*One newly diagnosed family found that the diabetes care on Ward 5 was inadequate with their daughter being given a sugar based paracetamol instead of sugar free, which led to problems with blood glucose control.*

*Jo stated that when her daughter was commenced on mdi the main concern of the hospital staff was who would administer the lunchtime injection – no education was given about the increased risk of hypos with mdi.*

*Sue, Jo & Nigel all expressed frustration at the fact the hospital does not give time to educating parents on carb counting when commencing mdi (in the case of some recent experiences 10 minutes education with a recommendation to buy the Collins Little Gem Carb Counting book). The dietician is not always present at clinic and comparisons were made with the excellent level of dietician support given to families whose care has been transferred to UCL.*

*Other positive experiences of families attending UCL were discussed & comparisons made with the service received at MK hospital including the*

*excellent level of education provided to schools (PDSN travels from London to MK to do this), the presence of a play therapist at clinic (and the support she gives during the taking of annual bloods, during pump school etc) & the availability of psychological support to those children needing it. Access to play therapists and psychological support from MK hospital has been difficult to obtain over the past two years by parents present.*

*Alistair expressed concern that there was a lack of vision/direction with the service offered by MK hospital and suggested they look at other leading hospitals like UCL to work in a consultative role to develop the service we have. Jo stated that UCL has already been working with other local authorities to develop plans to support children with diabetes in schools. Could this be explored by Milton Keynes?*

*In the light of these comments Steve asked Dr Hicks if he felt that the PCT was getting short changed by the present service and asked if the contract for diabetes care could be enforced to meet the NICE guidelines he (Dr Hicks) had stated was their minimum expectation.*

Dr Hicks replied that it did appear that the tax payer was not receiving value for money with regard to the paediatric diabetes care contracted from MK hospital but felt this was not the only clinical area where this was true.

He then

- Queried who we as a group have as a point of contact at the hospital to enable our concerns to be heard & used to inform service development.
- Suggested we make contact with
  - i) PALs as a way of gaining fairly rapid engagement with clinical teams.
  - ii) John Needham at LINKs – a local involvement group who the PCT approach when they are seeking the advice of service users.
  - iii) Andy Peedles regarding the development of the web portal (Nigel has already been liaising with him).
- Was keen to ensure that the group will in future have an effective route into hospital.

Dr Hicks agreed that either he or Gillian Prager (the Director of Standards and Public Engagement, NHS Milton Keynes) will attend a meeting in three months time to discuss the progress that has been made.

## **Forthcoming Events**

### Mead Open Farm – 16<sup>th</sup> May

Don't forget to bring a picnic if you don't want to eat in the restaurant on the day!

### Milton Keynes Country Show – 30<sup>th</sup> May

We have a stall at this event with a view to raising the profile of the group and some money by selling home baked goods, hand made crafts etc and having a tombola. If anyone can contribute anything at all nearer the day, or if you are baking Alastair can possibly collect or you can drop donations/goods in to Tracey's workplace in Newport or to the shop in Olney. Either way give let us know on 07949 998464.

## **Actions**

Steve to make contact with PALs

Nigel to make contact with John Needham – LINKs

## **Next Meeting**

Monday 11<sup>th</sup> May – County Arms, New Bradwell