



**Monday 18<sup>th</sup> May 2009**

**Present**

Viv, Neil, Nigel, Alistair, Tracey, Steve

Rachel Lewis - PALs

**Apologies**

Steve – Rachel was welcomed and introduced to the group. She was briefly told of the previous meeting with Dr. N. Hicks and that he had advised us to contact PAL's with the view of getting our voice heard within the hospital.

Rachel – Spoke of the relationship of the PAL's organisation within the PCT and she said that they look at not only complaints but praise and general communications between patients and all depts. within the PCT including GP surgeries, opticians and the hospital.

Neil-We need to look at who is responsible for monitoring the quality of service within the hospital and asked Rachel who would be the person we need to talk to.

Rachel – Various people and groups look at quality including the PCT who expect standards and targets to be met by the service providers. If there is a problem with the service the PCT can place it on 'notification' with the contract potentially going out to tender.

Neil- Whilst the NHS is run on similar lines to that of a business and putting out contracts to tender it is not really effective as the more lucrative contracts could be the only ones competitively tendered for. It was agreed amongst the group that we do not know what the service agreement for paediatric diabetes care says or whether there is one specific to paediatric diabetes care.

Steve – As well as targets and standards we really could do with someone with the drive and vision to improve the services that we receive to a standard as experienced elsewhere. Many of the good experiences elsewhere and more positive aspects as experienced at MKFH are down to simple things like good communication, which should not cost a great deal. Is there any way this leadership and vision can be brought to Milton Keynes.

Nigel – Dr Bursell is new consultant within the department and he has indicated that the hospital will be looking towards pump therapy in the future but is there a written plan as to how the hospital will move towards this? Has anyone been asked to do any work in this area? What is the short / medium term plan with regard to paediatric diabetes care?

Nigel-Asks whether the 'LIT' Local Implementation Team would be a group which might listen to what we have to say.

Rachel – The Healthcare Commission (*now believed to be the 'The Care Quality Commission'* <http://www.cqc.org.uk/>) is a body that all healthcare providers have to register with and they ensure that standards are met within 7 areas.

Alistair – What we are finding is that the NHS keeps changing how it is set up and it difficult to ensure people take responsibility. They should be using the wealth of knowledge that parents have to help them but generally they seem to have barriers between us and them although we have seen that there has been some positive interaction with Jackie the new paediatric diabetes nurse.

Nigel – Agrees with what Alistair says and that parents of children with diabetes are in quite a unique position that we prescribe what levels of drugs we administer to our children.

Rachel – With regard to finding out more information about local services we can use the Freedom of information act to get most information including the local service agreement between the PCT and hospital.

Neil – As several patients have moved to other hospitals has anyone at MKFH look at the numbers and the circumstances to these transfers of care.

#### Other business.

20<sup>th</sup> June Diabetes UK are holding a course 'Insulin pump services for children' in Camden, London Neil, which either Jo or Steve hope to attend. Diabetes UK need to be informed asap to ensure the event goes ahead.

Nigel on Wednesday 20<sup>th</sup> May 2-4.30pm a meeting is being held of the Children and young people with diabetes network. The minutes and details of the forthcoming meeting were discussed and although the format of the meeting is unknown there should be information relevant to the group.

Nigel has expressed an interest in doing a sponsored run possibly in aid of JDRF.

Jo has a place for the JDRF in the Adidas Women's 5km run on Sept 6<sup>th</sup> at Hyde Park – London.

Tracey - Sainsbury's have a current initiative to support local charities and it might be worth looking into.

The Drayton Manor trip is will no longer be going ahead as unfortunately funding at this time could not be secured from Diabetes UK; instead we will meet for a picnic at Salcey Forest on 4<sup>th</sup> July 11.00 main car park.