

# INFORMED CONSENT AFTER THE BABY IS BORN

The lack of informed consent that currently exists for much of the testing and screening that occurs during pregnancy is unfortunately not confined to antenatal care and the increasing number of screening procedures. Once the baby is born new parents find themselves under pressure to agree to what are regarded by most health professionals as routine practices. The administration of Vitamin K injections, Guthrie card heel pricks, and vaccinations are but the beginning of a series of decisions faced by parents in the immediate postnatal period.

## **Vitamin K injections**

The issue of the need for Vitamin K, whether administered orally or in the form of an injection, in order to prevent so-called Vitamin K Deficiency Bleeding (VKDB) in babies was covered in depth in an article in the June 2006 issue of the MSCC newsletter. Suffice it to say that few parents are given good information about the role of Vitamin K during pregnancy, the significance of the natural levels of Vitamin K in a newborn baby's blood, or the "need" for an artificially large dose of this vitamin immediately after birth. As a result the vast majority of parents go along with the tacit or openly expressed recommendation by their LMC to have their newborn baby given a Vitamin K injection, while a small percentage opt for an oral form of Vitamin K, with only a very few deciding not to give their baby any Vitamin K supplementation at all.

The lack of any real level of informed consent only becomes obvious when parents decide not to have their baby given Vitamin K. Various tactics are often used to persuade them to change their minds. These may include such measures as receiving a visit from a paediatrician (if the woman has given birth in hospital) who will explain the terrible danger that their baby is in of experiencing one of the three forms of VKDB, comments from other staff along the lines of "Why would you want to take the risk of your baby dying from VKDB?" or threats to refer the matter to CYPFS (the Children and Young Persons and their Families Service) and have the baby removed from their care for failing to supply the "necessities" of life.

## **Guthrie Card heel pricks**

The use of blood samples taken two or three days after birth through a heel prick in order to test for a number of metabolic disorders has been around since the 1960s. The programme, now referred to as the Newborn Metabolic Screening Programme, currently tests for 28 metabolic disorders. The blood is placed on a card known as the Guthrie card which includes information about the baby such as the baby's name, sex and date of birth. Over the past few years there have been increasing concerns expressed regarding the privacy, storage and future use of the Guthrie cards which is now in danger of becoming a de facto DNA database.

Again this "routine" procedure, while often quite distressing for new mothers to consent to and witness, is one that the vast majority of parents agree to have done. The tests on the blood spots enable the identification of a number of rare disorders that if detected soon after birth are able to be successfully treated.

However, the degree of informed consent involved in the collecting of this blood sample only gets tested on the extremely rare occasions when parents refuse. Health professionals can react very strongly. They may get very hostile and even resort to attempting to intimidate the parents into agreeing to the test. In a complaint to the Health & Disability Commissioner in 2001 one new mother described how the paediatrician repeatedly threatened first her and then her partner that if they did not consent to the test he would approach CYPFS to have their child taken off them. She said "this was the *ultimate* intimidation." After the paediatrician repeated these threats to the

woman's partner he told both parents he did not want them to leave the hospital without agreeing to the procedure.

In his defense, the senior paediatrician told the Commissioner that he had not experienced a refusal by an "informed" parent to consent to the test in 15 years of clinical practice, that he had acted in good faith, and that he believed he had acted in the best interests of the baby.

Fortunately, the HDC's opinion made it very clear that "the parents, as the child's legal guardians, had the right to refuse the test. The test is not mandatory under the law." The Commissioner also found that the paediatrician's approach was clearly intended to coerce both parents into a course of action they did not wish to take and was thus in breach of Right 2 of the Code of Consumers' Rights – every consumer has the right to be free from discrimination, coercion, harassment, and exploitation. He recommended that the paediatrician write a letter of apology, something the doctor felt somewhat uneasy about doing "because throughout the whole affair [he] held the interests of the child as being pre-eminent and so far during the investigation ... the child's interests have not been paramount."

It is not recorded whether the doctor ever did write and apologise to the parents as requested by the HDC. However, what this case clearly revealed was the amount of covert or overt coercion that parents come under if they don't immediately fall into line with the course of action recommended by their or their baby's caregivers.

### **Vaccinations**

This is another area in which parents can find it difficult to get access to anything other than the information that both health professionals and the Ministry of Health want them to have. Some years ago when the MSCC supported parents being given both the information on vaccinations produced by the Ministry of Health and that put out by the Immunisation Awareness Society, the MSCC co-ordinator was threatened with being sued by the then Director of Public Health, Dr Colin Tukuitonga. At that time Dr Tukuitonga was also suggesting that midwives should not be paid if they provided parents with anything other than the MOH's brochure on immunisation.

The MSCC made a formal complaint to the Health & Disability Commissioner but this was not taken seriously by either the HDC or the Ministry of Health.

That this is still an issue was highlighted last month when the MSCC received an email concerning the Ministry of Health Immunisation Stakeholder Group and the distribution of immunisation promotional material by the MOH. It is obvious that the Ministry is still having considerable difficulty with the concept that parents have a statutory right to information that is provided in a way "that is readable, appropriate, understandable and unbiased" as well as the right to make their own decisions about vaccinating their infant. The email pointed out that the Ministry was at risk of breaching its own code of ethics in using a piece of unpublished piece of market survey as if it was real piece of research and thus evidence for the actions it was recommending, the market survey was undertaken in connection with Wyeth, the drug company that supplies the vaccine in question, the complete lack of regard for the concept of informed consent, and the material provided to those attending the meeting referred to midwives and midwifery in a way that was "scurrilous" and also did nothing for the credibility of nursing. "Such scaremongering and misinformation is in danger of seriously raising questions in the minds of those that it insults."

The fact that there was a representative from Wyeth, the pharmaceutical company that manufactures these vaccines, but no representation from consumer groups is also indicative of the Ministry's total disregard for conflict of interest situations, and lack of awareness of the need for a balance of viewpoints to be included when forming an Immunisation Stakeholder Group.

Little wonder that parents interested in obtaining information other than the biased pamphlets and booklets provided by the MoH often report great difficulty in getting access to an alternative and unbiased view. The Ministry's efforts thus far has been to do all it can to discredit other community organisations who promote the concept of making an informed decision around the increasing number of vaccinations being recommended and who attempt to provide information that questions the efficacy and/or safety of various vaccines.

In the light of this, the MSCC believes there is a need for health professionals to recognise that the Code of Consumers' Rights give parents the legal right to have access to information from more than one officially sanctioned source and to make their own decisions about the tests and procedures they want their baby to have.

As with the antenatal screening tests and other procedures, those carried out in the postnatal period must also comply with the need to gain proper informed consent from parents.

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