Case Conference

A couple, Mr & Mrs G., came for their first visit to the genetic counselling clinic in 1989, the wife pregnant and worried about the history of ocular albinism in her two brothers. This condition affects only males, and can be transmitted by females (as in haemophilia). Her brothers are registered with the Blind Foundation, but have sufficient vision to read computer-enlarged writing and can get around town using a white cane.

It was possible she could be a carrier. Several years ago, during her first marriage, she had had an eye examination herself to see if she could be a carrier, and she appeared not to be - but this examination was not definitive. Her two young daughters (three and five years old) were also studied, and each seemed to be clear. But it did remain possible some or all of these females could be carriers. The carrier state causes no problems at all to the (female) person's vision.

In those olden days (1989) when Mr & Mrs G first attended the genetic clinic, no "gene testing" could be done to determine her carrier status, nor in the pregnancy, and so she chose to have amniocentesis at 16 weeks for fetal sexing. The fetal sex was male, and so she then had an abortion, on the grounds that it might have been an affected male. She said she could not live with herself if she had knowingly passed this gene for a major visual handicap to a son.

An aeon later (1992) they sought genetic advice when she again became pregnant.

Now, a "gene test" could be done: and, in fact, it turned out she *was* a carrier. She had a test in pregnancy (this time chorionic villus sampling at 10 weeks), and again it was male and, from the gene study, it was possible to show that the gene for ocular albinism definitely had been passed on. For a second time, she had a termination.

Now (1993) she's insisting that her daughters - now 11 and 13 - know whether they are carriers or not. She says that, if neither is, she would chance a further pregnancy; if one or both are, she's "planted enough trouble for the next generation", and would call it a day. She was told that, according to current policy guidelines, it was not possible to test her daughters without their knowing and understanding the reasons for this. (The girls know their uncles don't see very well, but don't visit them very often. They have not reacted too well to their mother's remarriage, and there has been some problem with school truancy with one of them.) She phoned back later, saying she had talked it over with her daughters and they both wanted to be tested "and anyway you were prepared to do an eye test when they were little to see if they were carriers, so what's the difference now?" She demands an appointment to bring the girls in for blood sampling, for the purpose of doing the gene test in respect of their own carrier status.

Should her request, which she claims to be making on behalf of her daughters, be acceded to?

COMMENTARY 1

Richard Savage and Shona Campbell-Savage
Primary and Secondary Teachers respectively (and proud new parents), Oamaru.

We believe that there are several factors to consider regarding the mother's request for her daughters to be blood sampled. Any decision would have to be considered alongside future repercussions for the daughters and the effect on the relationship between the mother and her new husband. Some of the information given regarding family dynamics would need to be clarified before a decision was made.

Given the brief family history, we feel that there may be problems within the parents' relationship that we are not aware of. For example, the school truancy of one of the daughters is probably symptomatic of a problem elsewhere - could it be due to the fact that the daughter does not feel comfortable with the new situation at home? Also, the father is not mentioned at all. What are his feelings regarding a pregnancy, knowing the risk of conceiving a male with ocular albinism or a female who is a carrier? Surely, his thoughts should be equally as important as the mother's.

If the daughters were to be blood sampled and found to be carriers, how would the step-father react to his step-daughters? We can imagine that he may well feel resentful towards them if a positive test means he and his wife will not have children. If this did happen, would it be fair for such young and impressionable people to be held responsible for an adult's childbearing decisions?

The girls are both at an age where their bodies are going through major hormonal changes and they are entering adolescence. They will probably already be increasingly aware of their own sexuality. If they were to have a blood sample taken and if they were found to be carriers, it is possible that this may influence their ability to form normal relationships with their male peers now and in the future, knowing they could have babies with major problems. They may feel 'abnormal' themselves as a result, which could have detrimental effects on their self-esteem and confidence at such an important stage in their lives. The truancy problem could therefore just be a hint of other problems that could occur, at home, at school and socially.

We are not convinced either that the girls are fully aware of why their uncles "don't see very well". Have they heard of ocular albinism, how it occurs and the implications of it? Perhaps the parents should have begun to explain some of the factors relating to their uncles' condition at an earlier stage, that is, only giving the facts that are appropriate to their age and understanding. The truth should never be hidden from children leaving them either never knowing, or else getting an awful shock all at once and maybe at a time when it is too late. Rather, a `drip

feed' of the truth would lessen the frightening impact of the fact that they may well be carriers. The possibility of them being carriers is something that they should definitely be aware of along with available tests to check the genetic status of the pregnancy if and when they consider pregnancy later in their lives. It is their right and the parents' responsibility to ensure this happens.

In the past, the mother has made decisions regarding her pregnancies irrespective of her daughters and their genetic status. Over time and with new techniques of gene testing being developed, the chorionic villus sampling at ten weeks enabled an early decision to be made regarding the future of the pregnancy in 1992. The chorionic villus test has to be preferable to waiting until sixteen weeks for amniocentesis and then having to make a decision after that. Any decision to have a termination is difficult and the loss of a baby will be painful at any stage for the parents.

But, there is still a chance that a pregnancy between the mother and her new husband may be successful and not have a male with ocular albinism or a female who is a carrier. They would therefore need to weigh up their desire to have children versus the inherent risks involved before deciding whether to try to conceive.

The fact that the mother is "demanding" that her daughters be sampled despite current policy guidelines also indicates that the daughters may not be fully aware of what the sampling or condition involves and also hints at a possibility that the mother may wish to "pass the buck" of blame onto someone else if she does not wish to go through the problems of a high-risk pregnancy with a likely termination. This is of some concern.

With the information given and for the reasons explained, we think that her request for her daughters to be blood sampled should be declined.

COMMENTARY 2

Mark Henaghan
Senior Lecturer in Law, Otago University

There is no statutory legal requirement to carry out the test. Courts are reluctant to require doctors to treat patients or carry out tests which are against the clinical judgment of a doctor. Because of ACC in New Zealand it is most unlikely that later civil action could be brought against a doctor's refusal to test on the basis of owing a duty of care to the girls or their offspring. Whether any duty had been breached would be most likely determined by what a reasonable body of medical opinion would do in the situation.

So should the test be carried out? In whose interests is the test and who has the right to consent to it? As a guardian of the children, the mother has a legal right to consent on their behalf to any medical procedure when it is "necessary" or "sufficient" to do so. Implicit in this legal licence to consent is that it will be for the benefit of the children. The leading New Zealand case on parental consent (which included sterilisation) makes it clear that the mere fact of consent by a parent does not put the doctor in the clear; the doctor must be clear the consent is informed and that the procedure is for the benefit of the children, otherwise the doctor may be subject to possible "civil, criminal, or disciplinary proceedings" (to quote the Judge in Re X [1991] NZFLR 50). The issue of "benefit" is difficult here. To know one is a carrier is some useful personal information, but the main benefit at this stage appears to be for the mother not the children.

The common law does recognise that once children (of any age) have sufficient understanding and intelligence to recognise the repercussions of a decision then they can consent on their own behalf to medical decisions. Is this the sort of medical decision these 11 and 13 year olds would understand given the current state of their lives? Is it at all relevant to the current state of their lives? It is my opinion that on balance (unless the children clearly want and understand the test and its repercussions) the mother's request should not be acceded to.

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Cases could cover areas of clinical and community medicine, public health or research, and could involve medical, nursing or paramedical professions. Cases can be written from the perspective of users or providers of services.

Cases need to be specific about clinical details, and provide sufficient detail to identify surrounding influences and relationships, but all identifying information should be altered or removed to ensure complete confidentiality for individuals and institutions.

Correspondence or enquiries to:

Barbara Nicholas,
Bioethics Research Centre
P.O.Box 913 Dunedin
Fax 03 474 7601