

Involving Fathers in Ante-natal Screening for Sickle Cell Disorders: Improving Informed Decision Making

Recommendations from the Project for Genetic Counsellors

- ➊ Having time with a specialist is highly valued by all parents but they feel that they cannot always articulate their questions. Make sure that they feel supported to ask 'stupid questions' and ensure access to interpreters if required. Make sure mothers and fathers get to ask all their questions.
- ➋ Ensure equity in services and access to all reproductive choices for everyone. This means giving choices to couples with carrier status and both men and women who have sickle cell.
- ➌ When dealing with young men explain how to instigate conversations with peers about sickle cell testing. Highlight role models and positive links to sickle cell to combat possible stigma.
- ➍ Be sensitive to the lack of awareness and information about sickle cell in British society. It is still perceived as a 'black disease', so show understanding to how this may affect men's conceptions of identity and understanding of testing.
- ➎ Be sensitive to the differing socio-cultural background of mothers and fathers and role of extended family.
- ➏ Timing is crucial for parents. Test results have to be given early to enable men and women to make informed choices that they find difficult.
- ➐ Check information given about carrier status and why a card is given. Explain specific

situations a person may encounter such as; operations, high altitudes and why donating blood is possible.

- ⊕ Make sure that you explain that prenatal diagnostic testing is neither a cure nor a treatment for sickle cell and has a risk of miscarriage. Explain why you are giving this choice but also that the child can be tested after birth.
- ⊕ Some fathers may only find out they might be carriers after a child is born. Ensure access to counselling services for these fathers.
- ⊕ Ensure reproductive choices are given for the next pregnancy.

A copy of the final report and resources can be found at:

http://www.york.ac.uk/media/healthsciences/documents/research/public-health/23116_A4_report%20v3.pdf

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