

List of Sex Linked Genetic Diseases

Introduction

This paper summarises the views of various professional authorities on the desirability of drawing up a list of sex linked genetic diseases. It also sets out the difficulties envisaged in including the list in the Human Reproductive Technology Bill (the “Bill”) or its subsidiary legislation.

Views of professional authorities

2. In response to the enquiry by the Provisional Council on Reproductive Technology (PCRT) on sex linked genetic disease in relation to sex selection, the UK Human Fertilisation & Embryology Authority commented that it would not be appropriate for there to be a list of genetic disorders which could be selected against, as such a list would necessitate the task of defining what is considered serious enough for inclusion and would therefore be arbitrary. The Authority concluded that the decision should be left with the clinicians and parents in each individual case, taking account of the welfare of the child to be born and that of any other children in the family.
3. The Fertility Society of Australia replied that they had no guidelines on this topic.
4. The Hong Kong College of Paediatricians considered that the setting up of a list of severe sex linked genetic disorders for the purpose of sex selection is both impossible and impractical on the grounds that whether a condition is severe enough to warrant abortion may be quite subjective, and such subjective

feeling is likely to change with time. The College suggested that the family concerned should receive proper and comprehensive genetic counselling from qualified professionals so that an informed decision can be made by the parents. The College also agreed that for small minority of sex linked genetic disorders that may not have any prenatal diagnosis nor effective treatment, sex selection should be allowed as a last resort to prevent the birth of an affected child.

PCRT's view

5. Having noted the comments from various authorities and deliberated on the issue, PCRT agreed that a non-exhaustive list of sex linked genetic diseases without defining the severity of diseases would be provided in the Code of Practice (COP) for reference purposes.

6. There are over a hundred definitely-recognised sex linked human disorders or traits. A list of major sex linked disorders was directly extracted from a textbook on genetic counselling as a reference list in the COP which was endorsed by the PCRT.

Difficulties envisaged for putting the list in the subsidiary legislation

7. It should be noted that this list is intended to be a reference list only. If this list is put in the subsidiary legislation, it may introduce operational difficulties because:

- many rare diseases are excluded;
- the list might have to be changed from time to time due to discovery of new disorders;
- and

- it will take more procedures, hence longer time to keep the list up-to-date if it is put in the subsidiary legislation.

8. Besides, it should be noted that the severity of diseases in the list is not defined because it would be difficult to do so. Different people would have different perception and acceptance level of the severity of a sex linked genetic disease, and it would depend more on the counselling process. Moreover, the severity of diseases will change with the advancement in the treatment of genetic disease.

Proposed monitoring mechanism

9. As it stands, the Bill includes gender selection achieved or intended to be achieved by means of a RT procedure as one of the RT procedures and prohibits its use for non-medical reasons. Its application to avoid the birth of a child with sex linked genetic disease will be subject to fulfilment of certain conditions. Moreover, the COP requires RT centres to report to the Council on all cases of sex selection achieved through RT. Through this reporting arrangement, it is considered that the Council would be able to effectively monitor the conduct of such activities by RT centres.

Health and Welfare Bureau

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