



A moral and social dilemma

Lucy is 17 years old and she has a condition called spina bifida. She has had this developmental disorder since long before she was born. It was obvious at birth that she had a serious form of the condition; in her lower and middle back she had several openings along her vertebrae causing her spinal cord to be exposed. Several neurosurgical operations over her young life have given partial relief. Infections to the sites had required several emergency admissions to the Regional Neurological Centre. The life expectancy and quality of life for Lucy is hard to predict. On a positive note, Wikipedia lists several paralympians among people who have met the physical challenges that this disorder has caused.

The moral dilemma that arises is this: Many cases can be detected before the infant is born, but only if the appropriate tests are performed (see footnote regarding these tests). However, both false positive and false negative test results can occur. Counselors, who are specially trained to deal with prenatal screening, are usually available to help the mother deal with what the tests mean, as well as the limitations of the tests. There is no cure for the severe form of the disorder and many victims will be severely physically and mentally handicapped. If the result is positive, the mother may elect to have a therapeutic abortion. Should it turn out that the procedure showed the fetus was normal (that is, the tests were wrong in predicting spina bifida) then the anguish to the parents would be tragic.

The social dilemma that is associated with this particular developmental disorder



supplement of 400 micrograms of folic acid. The completion of the neural tube's development occurs in the first few weeks of pregnancy so waiting until a pregnancy is confirmed before taking the supplement may be too late. It is likely that many fertile women have a diet that lacks an adequate amount of folate and socio-economic circumstances may mean that fresh fruit and vegetables are considered to be a low priority.

Footnote:

Procedures that are used for the prenatal diagnosis of neural tube defects include ultrasonography and laboratory tests to detect an excess of alpha fetoprotein (AFP) in the mother's blood and in the amniotic fluid.

Note:

Amniotic fluid is held within the amniotic sac which in turn is composed of two membranes: the amnion and the chorion. In Ontario, as well as in other jurisdictions, the M.S.S. (maternal serum screen) is used for prenatal testing. This tests for 3 or 4 different proteins using the

is that many of the cases may be due to a deficiency of folate in the mother's body. The cause of the condition is a defect in an embryonic structure called the 'neural tube'. Normally this develops to form the fetus's spinal cord and the brain as well as the tissues that normally enclose them. For this process to be completed, folic

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acid (folate) is required, otherwise a variety of neural tube defects may occur, spina bifida being one of the most serious. Dried beans, citrus fruits, and green vegetables are dietary sources of folate. Folic acid is used as a supplementary source. Many experts recommend that all women in the child bearing age group take a daily

mother's blood; one of these tests is for AFP. Furthermore, sophisticated testing may include amniocentesis. In this invasive procedure, amniotic fluid is carefully sampled. In each type of sampling, blood and amniotic fluid, an excess amount of AFP is consistent with a diagnosis of a neural tube defect. JLB ❖