

POSITION STATEMENT ON PRENATAL GENETIC TESTING

With this Position Statement on Prenatal Genetic Testing, the aim of the Down Syndrome Society of SA Inc., (DSSSA) is to foster a climate of understanding and mutual respect for the dignity, worth and equal rights of all people, regardless of handicap or disability. All people, including those with Down syndrome, are a part of their local communities, and shall be recognised as having a rich contribution to make in the development and well being of the human community. The vision of the DSSSA is ‘...opening doors together to enrich the lives of people with Down syndrome.’

The Maternal Serum Screening Test establishes the probability of a pregnant woman having a child with Down syndrome or spina bifida and other neural tube defects. The DSSSA wishes to address screening in relation to Down syndrome only. We believe that the widespread use of genetic screening for the purpose of identification and abortion of foetuses with Down syndrome may adversely affect the quality of life for all persons with Down syndrome in our community. This adverse effect could potentially reduce funding and support services to individuals with Down syndrome and may encourage negative attitudes of society towards persons with Down syndrome.

The following statements are in reference to prenatal genetic testing. Where used in the foregoing statements, and in any other DSSSA publications, the term “*prenatal genetic testing*” is intended to include maternal serum screening.

1. We believe the primary goal of prenatal genetic testing should not be to reduce the birth prevalence of Down syndrome in the population. Its use should be directed towards the provision of improved health care for the mother and baby. The prenatal recognition of Down syndrome could allow for the preparation of parents and the medical caregivers regarding any necessary medical or surgical procedures to be carried out either before or after the baby’s birth.
2. Prenatal genetic testing should be voluntary. The woman or the couple should receive counseling that is comprehensive and provided in a language that is easily understood by them. Prior to any consent for prenatal genetic testing, the couple should be given accurate and up-to-date information on all the relevant issues surrounding prenatal genetic testing and Down syndrome. This information should be provided in a balanced manner. Each woman or couple should be allowed to decide whether prenatal genetic testing is appropriate for them based on informed choice. An appropriate period of time should be allowed between receiving the information and deciding to consent whether or not to proceed with the test.
3. Following a test result, which implies that the foetus may have a probability of a chromosome abnormality such as Down syndrome, the woman or couple should be provided with detailed and balanced information regarding the options available to them. This information should be provided by knowledgeable and qualified health care providers such as those found in accredited genetic centres. Balanced information should be so recorded for the woman or couple to review at

DOWN SYNDROME SOCIETY OF SOUTH AUSTRALIA INC.

their leisure. Opportunities to have the woman or couple speak to parents of children with Down syndrome should be offered.