

**POSITION STATEMENT ON THE HUMAN GENOME PROJECT
(Adapted with permission from the Canadian Down Syndrome
Society)¹**

With this Position Statement on the Humane Genome Project the aim of the Down Syndrome Society of South Australia Inc., (DSSSA) is to foster a climate of understanding and mutual respect for the dignity, worth and 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 recognized as having a rich contribution to make in the development and well being of the human community. The vision of the Down Syndrome Society of SA (DSSSA) is ‘... opening doors together to enrich the lives of people with Down syndrome.’

The Human Genome Project is a worldwide scientific endeavour to map the entire human genome (all the genes that make up human DNA), a task that was recently announced to be nearing completion. The information gathered from this project will one day facilitate improved detection, treatment and cure for diseases and/or disabilities that are caused, or partially caused by genetic mutation or abnormalities. It is the extra copy or extra fragment of chromosome 21 that causes the characteristics of Down syndrome; a condition occurring in approximately one in 800 births in South Australia. The society wishes to address the potential outcomes of the Human Genome Project in relation to Down syndrome.

Prenatal genetic testing is already commonplace. The concern of the DSSSA is that genetic screening has largely been a tool to eliminate as many disabilities as possible and thereby devaluing the lives of people living with disabilities. We believe the primary goal of any genetic research should not be to reduce the number of Down syndrome births but rather to provide improved health care and assistance to persons with Down syndrome, so that they may lead full and productive lives.² While testing can be done, the application of the resulting knowledge poses potential negative implications for people with disabilities. Ethical and legal issues raised by this research and resulting gene manipulation techniques will be even more complex.

The DSSSA is cautiously optimistic about the Human Genome Project’s potential applications and the effect they may have on people with Down syndrome. We support research on the sequencing and function of the genes that will help to better understand the condition of Down syndrome.

In May 2000 scientists identified all the genes located on chromosome 21. We anticipate that continuing research will identify which gene(s) on chromosome 21 are responsible for the more disabling characteristics associated with Down syndrome, such as intellectual difficulties, congenital cardiac defects, and immunological deficiencies. This may lead to devising treatments and/or therapies to improve the health and well being of persons with Down syndrome. How far reaching these treatments may be is mere speculation. We believe that research initiatives and

¹ Position Statement on the Human Genome Project – 2003 (Canadian Down Syndrome Society)

² For more information refer to the CDSS brochure *Prenatal Testing*

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legislation governing genetic testing and gene therapies should reflect the dignity, worth and equal rights of all people, regardless of handicap or disability.

The DSSSA is confident that new opportunities will emerge that will assist individuals with Down syndrome to maximize their full potential. Persons with Down syndrome enrich our communities and they have much to teach us about understanding, acceptance and appreciation for all life has to offer.