



Canadian
Down Syndrome
Society

Société
canadienne de la
trisomie 21

Prenatal Genetic Screening and Testing

The Canadian Down Syndrome Society is committed to ensuring the Down syndrome community in Canada is valued, supported and that individuals with Down syndrome are given equitable opportunities to contribute to society as fully participating citizens. We work to empower Canadians with Down syndrome and achieve this by raising awareness and providing information on Down syndrome for all life stages from prenatal to retirement years. We foster a climate of understanding and mutual respect for the dignity, worth and equal rights of all people.

Background:

Each year in Canada, 450,000 women become pregnant¹ and some decide to undergo optional prenatal screening and diagnostic tests to assess the likelihood of genetic conditions before the baby is born. Women can choose between different types of prenatal screening depending on the gestational age (how far along they are) and what is available in their province or territory. Our concern is that some women may make decisions about their pregnancy based on negative attitudes and inaccurate, outdated information about Down syndrome.

Position Statement:

The Canadian Down Syndrome Society (CDSS) respects the rights of women if they choose to undertake prenatal testing for genetic conditions, including Down syndrome, and to make decisions about whether or not to continue a pregnancy based on their personal circumstances and beliefs. The CDSS asserts that women should have access to fair, balanced and accurate information to support informed decision making when undergoing prenatal screening and diagnostic testing for Down syndrome.

The CDSS supports these following guiding principles to serve our position:

- It is essential that the information is realistic, comprehensive and includes more than medical factors associated with Down syndrome. Information provided to a woman and her supporters should include details on the psychosocial, cognitive and educational aspects of parenting a child with Down syndrome.
- The medical community should have access to and disseminate information about Down syndrome that is accurate, nondirective and helps expectant parents make informed decisions.
- We understand that women undergo prenatal screening for Down syndrome for their own reasons and values, including advanced preparation for the birth of their baby, and some women choose to obtain the information to help them decide whether or not to continue with the pregnancy.
- It is essential for a woman to be able to make a fully informed decision that is aligned with her values and to feel supported in that decision.

¹Rosseau, Francois et al. "PEGASUS-2 Personalized genomics for prenatal abnormalities screening using maternal blood: towards first tier screening and beyond" <<https://www.pegasus-pegase.ca/pegasus/>>

*Please quote fully and reference the Canadian Down Syndrome Society
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