



Society of Obstetricians and Gynaecologists of Canada  
Key Messages/Talking Points

Overview

This communications plan will address the responses to be undertaken by the Canadian Down Syndrome Society and Down syndrome groups/local contacts in response to recommendations of the Society of Obstetricians and Gynaecologists of Canada. According to their website:

*"Founded in 1944, the Society of Obstetricians and Gynaecologists of Canada is comprised of over 3,000 professional members, including gynaecologists, obstetricians, family physicians, nurses, midwives and allied health professionals. A leading authority on reproductive health care, the SOGC produces national clinical guidelines for both public and medical education on important women's health issues."*

The January 6, 2007 edition of the *National Post* featured an article by reporter Siri Agrell, in which she wrote about planned recommendations by the SOGC regarding prenatal testing. The organization indicated that in the February 1, 2007 edition of their medical journal, recommendations would be made that all pregnant women undergo prenatal testing for Down syndrome.

These recommendations would include a nuchal-translucency test, followed by genetic counseling and amniocentesis. The nuchal-translucency test measures thickness of the fetus's neck – if excess fluid is found in this area it indicates that the fetus is in distress and might have complications such as microcephaly, heart defects, and other chromosomal problems. If thickness beyond the "normal" range is found, physicians are to recommend that their patients undergo genetic counseling – through their family doctor, obstetrician and/or a genetic counselor – followed by amniocentesis to screen for Down syndrome.

While it is important that information is presented to prospective parents about their child's health, the language used by the SOGC is extremely problematic. The executive vice-president of the SOGC, Dr. Andre Lalonde, made the following statement in the *Post* article:

*"Yes, it's going to lead to more termination, but it's going to be fair to these women who are 24 who say, 'How come I have to raise an infant with Down's syndrome, whereas my cousin who was 35 didn't have to?' "*  
*Dr. Lalonde said. "We have to be fair to give women a choice."*

The Canadian Down Syndrome Society was contacted by the same reporter in response to the article; in which Krista J. Flint was able to articulate the position of the organization regarding prenatal testing. The original format of these articles appears as appendices to this communications plan.

A public awareness campaign is planned for February 1<sup>st</sup>; this plan will detail the responses to be taken by the CDSS in anticipation of this execution date.

Organization's Goals

Three major goals of the Canadian Down Syndrome Society are involved with leadership, support and communication:

- \* **Leadership** – to be the primary Canadian resource on Down syndrome. Leading advances in social policy development, bioethics, human rights and social justice issues that are relative and responsive to the needs and desires of people with Down syndrome.
- \* **Communication** – to build public awareness and understanding of people with Down syndrome, their value, and their contributions to their families, communities and humanity through a comprehensive communications strategy, networks and events.
- \* **Support** – to support relevant research and the development of materials, tools and resources to enhance learning, well-being, community involvement, employment and life success for people with Down syndrome.

Many of the business direction of the CDSS centre around perception-changing; much of which has been directed by senior leadership to be undertaken through communications functions.

### Communications Goals/Objectives

The communications goals specific to the public awareness campaign responding to the Society of Obstetricians and Gynaecologists are as follows:

- \* **Clarified positions about prenatal testing:** Comments had been made to the CDSS about the article featuring Krista Flint, published on January 10, 2007, that indicated confusion about CDSS' position to prenatal testing in general. It seemed that the CDSS was not in favour of women undergoing prenatal testing; when in fact this is not the case. Communicating clearly that information is the main concern is a major communications goal; the objective to achieve this is strong key message development.
- \* **Positions about accurate and balanced information:** Information is a contentious issue – the medical community would argue that women deserve information about every challenge their baby with Down syndrome will face. However, one might wonder if parents need to hear that their new baby might face dementia at age 40; the point is that clear, succinct information needs to be construed. Also problematic is the issue of value-laden language; parents have indicated they were told their baby with Down syndrome would be “a severely retarded child who can't tie his shoes.” One can't call this information – it is biased opinion.
- \* **Ethics/Eugenics/Human Diversity Debate:** A major issue needing to be further discussed is the ethical debate of reproductive technologies and their effect in eliminated a subset of the human populations. While the medical community would advocate that such advances seek to increase choices and information for prospective parents, one could argue that this leads to an endless pursuit of perfection that has fatal consequences. A key message around this debate will be developed.

### Sensitivities

The testing method of amniocentesis is one for sensitivity in this debate; in the past one could argue that the technology should be cautioned because of the inherent risks presented to the fetus. However, new information has shown that amniocentesis is less dangerous than previously thought.

The announcement expected on February 1 echoes a recommendation made by the American College of Obstetricians and Gynecologists released on January 2, 2007. The ACOA recommends that **all women** – regardless of age – should “be offered screening for Down syndrome,” including a wide range of test including maternal serum triple screening, chorionic villus sampling, amniocentesis and nuchal-translucency.

The SOGC and ACOG recommendations are similar to the findings released by the *New England Journal of Medicine* in November 2005. That study revealed that the combination of an ultrasound, blood test

and nuchal-translucency test, can detect the presence of Down syndrome in a fetus as early as 11 weeks gestation.

The recommendations by the Society of Obstetricians and Gynaecologists of Canada are a three-part process: pregnant women under 40 will be first recommended to undergo a nuchal-translucency test; if abnormal fluid amounts are found in this non-invasive ultrasound technology, the patient will then be referred for genetic counselling and amniocentesis.

### Key Messages

- \* The Canadian Down Syndrome Society believes that information is powerful and necessary for families; we do not take issue with prenatal testing itself.
- \* We do not take a stance on abortion or against prenatal testing; we feel it is critical for prospective parents to receive information that is accurate, balanced and up-to-date. This information will allow parents to make the best decisions for their families
- \* Our members have told us that this information is not being communicated from health professionals; information is outdated, inaccurate and full of stereotypical, value-laden language such as retardation, defect, anomaly and chromosomal abnormality.
- \* People with Down syndrome are people first; the presence of Down syndrome is a part of that individual, not their sole characteristic. Value-laden language dehumanizes and degrades the value of people with Down syndrome as nothing more than a disability.
- \* The recommendations by the Society of Obstetricians and Gynaecologists are three-fold: patients will be referred for nuchal translucency, an ultrasound that can detect problems in the pregnancy; followed by genetic counselling and amniocentesis. The Canadian Down Syndrome Society does not take issue with any form of genetic testing itself; families should have access to this technology if they choose to. However, we are very concerned with the phase of genetic counselling. This is a critical time for families to receive balanced information about the realities of life with Down syndrome. The potential is huge for families to receive stereotypical and value-laden information about Down syndrome, which is a problem.
- \* Just as the Society of Obstetricians and Gynaecologists of Canada recommend prenatal testing for all pregnant women under 40, we would hope that the information communicated to parents be accurate, balanced and free of value-laden language.
- \* The Canadian Down Syndrome Society views Down syndrome not as a medical condition. Down syndrome is a chromosomal arrangement that has always existed. There are certain medical conditions associated with Down syndrome, such as congenital heart defects and gastrointestinal problems. Having Down syndrome does not guarantee these health problems, and many citizens with Down syndrome do not experience any health concerns. The incidence of health and learning concerns varies widely between citizens with Down syndrome.

A parallel would be that being female is not a medical condition; there are certain health concerns inherent for women, such as breast or ovarian cancer, but the disposition to these health concerns varies widely between individuals and is not guaranteed. Many women do not experience any health concerns.

- \* Down syndrome is referred to not as Down's syndrome. Unlike Lou Gherig's disease, also known as ALS, John Langdon Down simply discovered Down syndrome; he did not have it. Therefore, it is not possessive – the correct reference is Down syndrome.

- \* The Canadian Down Syndrome Society is seriously concerned that these recommendations are targeted specifically for screening Down syndrome. While fetal prenatal health is important for all parents, these recommendations seek to screen for and eliminate the existence of people with Down syndrome specifically. The targeting and elimination of this population is seriously concerning and unethical. There may come a day when people with Down syndrome do not exist in our society and the CDSS considers this unacceptable.
- \* Citizens with Down syndrome are an important part of the human family. We have spoken with many self-advocates – people going to school, working and getting married – and they are horrified that these tests seek to eliminate their very existence.
- \* People with disabilities are not the first group to be targeted for their existence – people of differing races, genders, religions and sexual orientations have all at some point been considered the undesirables of society. The inclusion of all these groups – including people with Down syndrome - makes our society more vibrant, welcoming and diverse.

### Key Messages – Down syndrome

#### **CDSS Mission/Vision/Values**

##### *Vision*

A Canada where ALL are welcome, we embrace diversity and we value everyone's genes equally.

##### *Mission*

To ensure equitable opportunities for all Canadians with Down syndrome. This means, to make sure all Canadians with Down syndrome have the right supports to give them the same opportunities that everyone else has.

#### **Strategic Priorities**

*Leadership* - to be the primary Canadian resource on Down syndrome. Leading advances in social policy development, bioethics, human rights and social justice issues that are relative and responsive to the needs and desires of people with Down syndrome.

*Communication* - to build public awareness and understanding of people with Down syndrome, their value, and their contributions to their families, communities and humanity through a comprehensive communications strategy, networks and events.

*Support* - to support relevant research and the development of materials, tools and resources to enhance learning, well-being, community involvement, employment and life success for people with Down syndrome.

#### **Types of Down syndrome**

There are three types of Down syndrome:

1. 95 per cent of people with Down syndrome have Trisomy 21, which means there is an extra #21 chromosome in each cell. For people without Down syndrome, there are only two copies of chromosome #21; individuals with Down syndrome have three copies of chromosome #21.
2. Two to three per cent of individuals with Down syndrome have translocation. During cell division, a part of the #21 chromosome breaks off and attaches itself to another chromosome, usually the #14 chromosome. About two-thirds of these translocations occur spontaneously while the rest are inherited from a parent. This type of Down syndrome can thus be inherited from a parent.
3. Two per cent of people with Down syndrome have mosaicism. In this case, some cells having 46 chromosomes and some having 47. The percentage of cells with 47 chromosomes instead of 46 varies from person to person.

## Key Messages

- \* Down syndrome is a naturally occurring chromosomal arrangement that has always been a part of the human family and is universal across racial, gender and socio-economic lines.
- \* Down syndrome was named after John Langdon Down, who discovered it in the late 1800s. Down syndrome is referred to as Down syndrome, not Down's syndrome. Unlike Lou Gehrig's disease (also known as ALS), John Langdon Down did not have Down syndrome - therefore it is not possessive, as in Down's.
- \* Down syndrome is present in about one in 800 births in Canada.
- \* Down syndrome is not a disease, disorder, defect or medical condition. People with Down syndrome are not "afflicted with" or "suffering from" it. Down syndrome itself does not require either treatment or prevention.
- \* There are some health concerns to be aware about: heart defects, hypothyroidism, some degree of hearing loss and vision loss. These vary from person to person. Preventative medical care with the family and physician are crucial.
- \* Down syndrome commonly results in an effect on learning style, and varies between individuals, just as physical characteristics or health concerns. The biggest challenge is to find effective methods of teaching each individual. Early intervention programs can help identify the best teaching methods soon after birth.
- \* Individuals with Down syndrome are people first. The emphasis should be on the person, not the disability. You might say, a person with Down syndrome, not "Down syndrome" child or "Downs baby."
- \* Down syndrome is a chromosomal arrangement present at conception; the term "birth defect" is not correct. People with Down syndrome usually have mild to moderate intellectual delay. The terms mental retardation and mongoloid are extremely inappropriate and outdated.
- \* Avoid generalizing people with Down syndrome as "always loving", "always smiling", or "perpetually happy." People with Down syndrome are not all alike. The diversity of characteristics among people with Down syndrome is similar to that of the general population.
- \* Avoid judgmental terminology. A person with Down syndrome is not "suffering from," "a victim of" or "afflicted with" Down syndrome. Down syndrome is not a disease and these references only diminish a person's dignity. Suggestions include "living with Down syndrome" or "has Down syndrome."