

The Canadian Down Syndrome Society is a national non-profit organization providing information, advocacy and education about Down syndrome. The CDSS supports self-advocates, parents and families through all stages of life.

We provide:

- * Up-to-date information through the CDSS website for individuals with Down syndrome, their families, educators, caregivers and professionals
- * Publications, including the CDSS magazine and monthly electronic newsletter, a toll-free information line: 1-800-883-5608, resource centre, and a network of over 50 Down syndrome groups
- * New Parent Packages containing a wealth of information for new and prospective parents

#283, 5005 Dalhousie Dr N.W. Calgary, AB T3A 5R8
Ph: 403.270.8500 Toll-Free: 1.800.883.5608
Fax: 403.270.8291 | www.cdss.ca
info@cdss.ca



Canadian
Down Syndrome
Society

Société canadienne du
syndrome de Down



Our Vision: A proud Canada, where ALL are welcome, we embrace diversity and we value everyone equally.

Our 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 as everyone else.

For information about Down syndrome, the CDSS New Parent Visiting Program, and informative workshops contact CDSS at 1-800-883-5608, or visit us on our website www.cdss.ca

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**WATERLOO REGIONAL
DOWN SYNDROME SOCIETY**

Sharing the News

A resource for medical and health care professionals with recommendations on how to tell parents about their child's determination of Down syndrome



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The first words to any parent should always be "Congratulations!" Your first words to a family have a lifelong impact.

As a medical and health care professional you are in a position to create a lasting impression when speaking to the parents of a child with a determination of Down syndrome. The terminology and information you give to families must be fair and balanced. This resource was created to give you some practical ideas and suggestions on fostering a greater understanding when providing direction and speaking with new families.



When giving a determination of Down syndrome here are a few things to remember

- * Value neutral language is important:
 - * Testing instead of Screening
 - * Prenatal Determination instead of Prenatal screening
 - * Likelihood or Probability instead of Risk
 - * Use sensitive language. Don't say "I'm sorry..." or that you have "bad news."
- * If appropriate, try to deliver the determination to both parents at the same time, in person and in private
- * Use people first language when talking about the child. She is a "baby with Down syndrome" not a "Down syndrome baby"
- * Have up to date printed information available for the parents. This information is available directly by contacting CDSS
- * Include the positive aspects of Down syndrome when explaining the determination. Children with Down syndrome are typically healthy children
- * Offer to connect them with a local support group or agency; most have programs for new parents and provide contact with other parents of children with Down syndrome. Call CDSS toll free at 1-800-883-5608 for more information or help locating a group
- * Be available to answer questions both initially and in follow up visits or phone calls from the parents
- * If a genetic counselor or social worker is helping with the initial determination, you both need to be providing consistent up-to-date information about Down syndrome
- * Encourage nurturing and if there are no immediate health concerns the baby needs to go home as soon as possible
- * Down syndrome is a naturally occurring chromosomal arrangement and is not a disease, defect, or negative medical outcome of pregnancy
- * Encourage breastfeeding and suggest that the mother speak to a lactation consultant. CDSS offers the resource, "Breastfeeding a Baby with Down Syndrome." Contact CDSS to receive the brochure
- * Accentuate the positives e.g. "Today most people with Down syndrome will learn to read and write, and participate fully in the community"
- * Ask the family if you may contact the local Down syndrome group and facilitate a resource parent to visit the new family as soon as possible. Contact CDSS for a comprehensive list of community resources in your area
- * Plan follow up visits or referrals to discuss medical concerns as parents are often overwhelmed upon the initial determination
- * Do not encourage institutionalization. Children should be included in all aspects of their family and community