



**Down Syndrome Association  
of  
York Region**



To the new family,

Congratulations on the birth of your baby! The families of The Down Syndrome Association of York Region want you to know that you are not alone. We have all been where you are right now. We know the overwhelming emotion you may be feeling having been told that your baby has Down syndrome. We also know that this child will bring you many joys in his or her life. He or she will show you compassion for others, pride in accomplishments and great determination amongst other things. He or she will change your life in more ways than you ever thought imaginable.

Please know that we are here for you – to offer support, education and friendships – whenever you need it. We are a large family-based group with members from throughout York Region. Wherever you may live, we have members who are willing to support you.

We have put together this packet of information as a start for you. These are the most popular “basics” to have in your library and should be used primarily as reference books. We have also added you to our monthly newsletter mailing list which will keep you updated on social and educational events in the area, as well as provide you with some local/national literature.

We have a wonderful group and can offer a large lending library, family activities, baby get-togethers, educational opportunities, a website, and of course, a lot of support to families.

That little baby that you have is a unique and precious gift, just like any baby, and we feel that it is important to remember that he or she is a baby first. Please contact us anytime with questions, concerns or comments.

Thank you and congratulations,

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## Welcome To Holland

By: Emily Perl Kingsley *Copyright Emily Perl Kingsley. All rights reserved.*

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you exclaim. "What do you mean, Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy." But there's been a change in the flight plan. They've landed in Holland, and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you never would have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around...and you begin to notice that Holland has windmills...Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. For the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever go away...because the loss of that dream is a very very significant loss.

But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.



## Where Do We Start?

Source: Getting a Good Start, Down Syndrome Association of Greater Cincinnati

Since each family is unique, there is not a single answer to this question. There are, however, five things that you can do immediately that will aid your peace of mind as you face the beginning of this new situation.

**Enjoy** your baby. These early months will pass very quickly. Do all the things you had planned to do before you learned that your baby has Down syndrome. If you are facing some major health condition with your baby, you may have to postpone some of these things — but only temporarily. This little bundle is a baby first and foremost; he or she just coincidentally has Down syndrome.

**Talk** to other parents who have a child with Down syndrome. Another family who has gone through what you are now facing is better able to understand your feelings. You may wish to talk with another parent, visit another parent or have another parent visit you.

**Explain** Down syndrome to your relatives and friends simply and candidly. How you accept your new little person will be reflected in the way others will accept him or her. The involvement of your family and friends can be a deeply supportive experience for you and a broadening one for them.

**Understand** that it is not your fault that your baby was born with Down syndrome. Nothing in the mother or father's activity caused this. Down syndrome occurs in all races, religions, environments, and at all income levels. The chromosomal abnormality that results in Down syndrome happens most often during the development of the sperm or the egg before conception, or immediately after the sperm and the egg come together at conception.

**Be Mom and Dad First.** As you learn more about your baby's condition and what you can do to help him or her learn and grow, you will find yourself in many different roles. One mom said, "Before I knew it, I was so wrapped up trying to be his teacher, therapist, his nurse or doctor, that there didn't seem to be any time left just to be Mom. I really wish I would have just enjoyed him more and been more of a mom to him and let everything else be more secondary...I felt like I always had to be 'working' with him. I know now that a normal, healthy family life is also so important to a child; a lot more so than a mother who is running herself ragged and not doing anybody any good." The key, then, is to strike a balance, keeping in mind that being a parent is your primary role.



## **Announcing the Birth**

By Nancy J. Murray, MS and William I. Cohen, MD

Source: When Your Baby Has Down Syndrome

Most importantly, your baby is a baby first and secondly, a baby who happens to have Down syndrome.

It is generally suggested that parents not wait to tell friends and family members about their baby having Down syndrome. Even though telling family members and friends about your child having Down syndrome may be one of the most difficult things you face, don't be afraid. Most parents who have a new baby want others to be happy for them and to extend best wishes.

Generally, the longer an announcement is put off, the harder it may be. Most people know very little about Down syndrome, so education is important. Some people will think back to people with Down syndrome that they knew as children. Their thoughts will tend to be out-dated because today, society is more accepting of people with disabilities. Children born with Down syndrome today have available to them more inclusive educational and community opportunities than children born even a decade ago. For some people, it may be extremely difficult to accept your child. That will be their problem and misfortune if they choose not to be a part of your family's life.

Generally, family and friends will follow your lead. Most people will want to sincerely share your experience in the same supportive and encouraging way as with the birth of any child. It may also be helpful to share your child's accomplishments throughout the years so that friends and family can continue to share developmental and educational milestones. On the other hand, it will also be helpful to share any difficult times, such as an illness or surgery. Oftentimes, a child with Down syndrome will cause others to reflect and find new, different, and deeper meanings in their own life.

About the Authors: Nancy J. Murray and Dr. William I. Cohen are with The Down Syndrome Center, Children's Hospital of Pittsburgh



## **Sample Birth Announcements from the Internet**

*Some parents choose to make an announcement about their baby having Trisomy 21 when they send their birth announcements so that people will not feel the need for an immediate reaction. Other parents feel that it is unnecessary to tell family and friends right away. Please see the following sample announcements as well an article about a family that decided to wait to make an announcement. We hope this information will be useful as you decide what's right for YOU.*

Letter inside birth announcement:

Dear Family and Friends,

Sean is a very special baby and his birth announcement doesn't exactly say it all. Sean is just adorable. He is 7 $\frac{1}{2}$  oz., 19" long, has a head full of silky hair and he was born with Down syndrome. He has chosen us to be his parents and we feel mighty blessed.

We wanted to give you time to adjust to this news, so you wouldn't feel the need to have an immediate response. We hope you will feel the same as we do -- we're happy and proud. We would like you to see him as we do, a beautiful baby boy. We also hope you will treat him just like any other baby, because he is a baby first and everything else is secondary to that.

We are still gathering information on Down syndrome and probably won't be able to answer questions right away. We would like to encourage you to call us and come to see Sean, though. He sleeps, eats, cries and coos just like every other baby. He looks exactly like his brother - he's just got an extra chromosome. We really think that Sean will be taking all of us on a beautiful journey. Please congratulate us and be happy for us - we're a family!

-- Rick and Lisa



From: [www.babiesonline.com/babies/e/emmajayne/](http://www.babiesonline.com/babies/e/emmajayne/)

### **Our Wonderbabe! The Story of Emma Jayne [photo]**

Emma was born on a blustery winter day in the arctic tundra known as the Midwest. She was delivered on February 13, 2004 via a planned C-section due to her most stubborn breech presentation.

She was 18.5 inches long and weighed 6.14 lbs.

Her parents, Emily and Khaled, were surprised to discover that she arrived genetically enhanced and sporting an extra chromosome. Emma has Trisomy 21, also known as Down syndrome; a secret she kept very quiet through her mother's well-monitored pregnancy. She continues to surprise her parents every day as her personality emerges and fills their lives with light.

She had them at hello.



## **Myths about Down syndrome**

Many people do not understand some of the basic facts of Down syndrome and instead hold beliefs about the condition based on common myths. Educating yourself about the condition can help you to avoid the limitations imposed by these myths. Knowing the facts can also help you provide your affected child with needed support, care, and a better opportunity to grow and develop to his or her full potential.

<b>Myth</b>	<b>Fact</b>
Down syndrome is a rare genetic order.	Down syndrome occurs 1 in 800 to 1,000 births.
Most Children with Down syndrome are born to older parents.	Most (about 80%) children born with Down syndrome are born to women younger than age 35. However, these women have an overall higher birth rate than those who are older. It is true that as a woman ages, her chance of conceiving a child with Down syndrome becomes greater.
People with Down syndrome are severely retarded.	Most people with Down syndrome have mild to moderate below-normal intelligence. Children with Down syndrome can learn, and like people who do not have this condition, their potential is unknown.
Most people with Down syndrome live in institutions.	Most children with Down syndrome live at home with their families and are active in educational, social, and recreational activities in their community. As adults, they may live in group homes and other independent housing arrangements.
Parents have difficulty finding helpful resources to help them while raising a child with Down syndrome.	Almost every community has parent support groups and other organizations directly involved in providing services to families affected by Down syndrome.



Children with Down syndrome must be placed in separate special education programs.	Children with Down syndrome have been included in regular classrooms. In some instances, they are in the regular classroom for part of the day, attending special classes for other subjects. Many children stay in the regular classroom curriculum.
Adults with Down syndrome cannot hold jobs.	Adults with Down syndrome can hold a variety of positions. Some people can be competitively employed; others need a supportive work situation.
The problems associated with Down syndrome can never be improved, corrected, or prevented.	Although Down syndrome cannot be cured, research is making great strides in identifying the genes that cause the characteristics of this condition. Some scientists believe that it may become possible to improve, correct, or prevent many of the problems associated with Down syndrome in the future.
People with Down syndrome are always happy.	People with Down syndrome have feelings just like everyone else. They respond to friendliness, and they are hurt and upset by inconsiderate behaviour.
Adults with Down syndrome are unable to form close relationships leading to marriage.	People with Down syndrome date, socialize, and form ongoing relationships. Some marry. Women with Down syndrome can and do have children, but there is a 50% chance that their children will also have this condition.

Reprinted with the express consent and approval of the National Down Syndrome Society (NDSS). Through education, research, and advocacy, NDSS works to ensure that all people with Down syndrome have the opportunity to achieve their full potential. For more information, call toll-free 1-800-221-4602 or visit the organization's Website at <http://www.ndss.org>.



## **LANGUAGE GUIDELINES**

- \* The correct spelling is Down syndrome. There is no apostrophe "s". The reason is because in English adding an apostrophe indicates that ownership is involved. Dr. John Langdon Down provided the first formal description of the syndrome, but he did not have Down syndrome and thus no possessive is used. Also, the "s" in syndrome is not capitalized.
- \* Use person-first language. Individuals with Down syndrome are people first. The emphasis should be on the individual, not the disability. For example: a baby/child/adult with Down syndrome, not "Down syndrome child" or "Downs baby".
- \* Down syndrome is a chromosomal anomaly that is present at conception. The term "birth defect" is not correct.
- \* Down syndrome is a developmental disability. People with Down syndrome usually have a mild to moderate intellectual delay. The term mental retardation is considered outdated in Canada and should be avoided. The term mongoloid is considered extremely inappropriate.
- \* 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 abilities and characteristics among individuals with Down syndrome can be best described as the same for 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. A suggestion would be "living with Down syndrome" or "has Down syndrome."



## Dear Mom and Dad, We need you too...

*When one of the children in a family has special needs it is natural and necessary that a lot of time and energy be directed toward that child. It is important to remember, however, that the other children in the family need you just as much. Following are some suggestions for maintaining balance within your family, written from a sibling's point of view.*

- 1. Be open and honest.** Accept the fact that my brother or sister has special needs and know that I will, too. What is the name of the condition that is affecting my brother or sister? Tell me what you know about it in a way that I can understand. Explain how all of the various specialists (physiotherapists, speech and language pathologists, etc.) are involved. Answer my questions as best you can, or help me find the answers.
- 2. Value each of us individually.** Don't compare our strengths and weaknesses. Remind all of your children of their unique qualities and praise us all for our contributions to the family.
- 3. Listen to me.** When my words or actions are telling you that something is bothering me please ask me about it. It may or may not have anything to do with my brother or sister, but at least I'll know that you still see me.
- 4. Don't give me too many caregiving responsibilities.** Remember that I am a child, too. It is important for me to have fun with my brother or sister, and to relate to him or her in that way -- not as an extra parent. Maybe there are other support services that can offer you the caregiving help you need.
- 5. Be fair.** My brother or sister should be treated as normally as possible, with no excuses made or special privileges given just because he or she has special needs. My brother or sister should be expected to do as much for him or herself as possible, instead of relying on me to do it for him or her. My brother or sister can help with household chores. When we know we've done something wrong we all need a consequence -- and plenty of praise, recognition and reward when we've done something right!
- 6. Schedule special time with me.** I know that my brother or sister needs extra time and attention, but I need you to notice me, too. Spending some time alone with you would mean a lot, even if it's just running errands or going to the park.



7. **Let us settle our own differences.** Don't expect me to have endless patience, understanding and tolerance. All brothers and sisters argue. In this way we are just like every other family. Working out conflicts ourselves helps us get to know each other and to learn how to compromise and co-operate.

8. **Put me in touch with other children who have a sibling with special needs.** I know they will understand exactly what it's like for me. Most of the time this isn't necessary, but if it is, get me some professional help in handling my feelings.

9. **Be part of the community.** Sign us up for activities we are interested in. Welcome friends and family to our home. Take us to visit them. Our family needs the support of the people we love. Being with our family makes them feel good, too.

10. **Recognize that we are mostly just like other families.** All families have difficulties that they must deal with; it's just sometimes not as obvious as with our family. All families have joyful moments, and we have lots of those, too. Having a child with special needs is *one* of the things about our family -- it's not the *only* thing.

Resources:

Brothers and Sisters -- A Special Part of Exceptional Families  
by Thomas H. Powell and Peggy Ahrenhold Ogle

Sibshops: Workshops for Brothers and Sisters of Children with Special Needs  
by Donald Meyer and Patricia F. Vadasy

Living with a Brother or Sister with Special Needs -- A Book for Sibs  
by Donald Meyer and Patricia F. Vadasy

Views From Our Shoes  
by Donald Meyer

It Isn't Fair  
by S. Klein and M. Schleifer