



Canadian  
**Down Syndrome**  
Society

Société canadienne du  
**syndrome de Down**

Summer 2010 • Vol 24 • Issue 1

21  
trisomy \*  
magazine



## Breastfeeding Myths

We are developing a new Breastfeeding Brochure to help you get all the facts.

## Rights of Persons with Disabilities

Learn more about Canada's Ratification of the UN Agreement and how you can protect the rights of your family.

## Provincial Aid Cuts

Governments are announcing cut backs. Has your province been affected?

## Table of Contents



- 2** News From the Frontlines
- 3** In the News
- 5** Breastfeeding Tips
- 6** UN Ratification on the Rights of Persons with Disabilities
- 7** Tying Your Own Shoes

## News From the Frontlines

Here at the Canadian Down Syndrome Society, we have been hard at work on a number of ongoing projects.

We have been busy putting the finishing touches on our **2010 Canadian Down Syndrome Conference** that will take place in Regina, Saskatchewan. The 2010 Conference in May will feature renowned international speakers, including Rosario Marin, Karen Gaffney, and Alvin Law. For the first time ever we will also host two separate Pre-Conference Workshops: one on supported employment and the other on inclusive education.

In addition to our annual conference, we have also been diligently researching information for a **new brochure about breastfeeding babies with Down syndrome**. The booklet will be produced and printed by the Canadian Down Syndrome Society. This heavily requested resource will be available this summer for distribution. Find out more about the development of this brochure on Page 5.

Keep an eye out for a number of new fundraising ventures we have been planning, as well. This summer we will be one of the participating charities in the **Scotiabank Charity Challenge** event. Join us in Calgary, where the CDSS Staff will be running and walking to help raise money and awareness.

The CDSS will also be traveling to Ottawa for the **Celebration of the UN Ratification on the Rights of Persons with Disabilities**. At the celebration the CDSS will be participating in workshops on the implementation of this new agreement. To find out more about the Rights of Persons with Disabilities see the full article on Page 6.



Canadian  
Down Syndrome  
Society

Société canadienne du  
syndrome de Down

21 Magazine is a publication of the Canadian Down Syndrome Society.

283 - 5005 Dalhousie Dr. NW  
Calgary, AB T3A R58

Toll-Free: 1-800-883-5608 Fax: 403-270-8291  
E-mail: info@cdss.ca | Website: www.cdss.ca



The number "21" represents the triplication of the 21st chromosome that is present in the naturally occurring arrangement of Down syndrome. It represents the beginning of the next twenty years in our compelling history. For the Canadian Down Syndrome Society, it also represents a certain coming of age, and the rights and obligations associated with this maturity.

Editor: Andrew Brown

Associate Editor: Stephanie Mamayson

Contributors: Ashlee Orr  
Kirk Crowther  
Chelsea Jones

## On the Front Cover

*From left to right:*

Logan Riley, Max Riley, and Tate Riley of Calgary, AB. Photography by Jamie Werner.

## Statement of Policy & Disclaimer

This magazine reports items of interest relating to Down syndrome and will provide a forum for others. The Canadian Down Syndrome Society does not promote or recommend any therapy treatment or product. The opinions and views expressed in this publication may not necessarily be those of the organization or its members. We wish to bring together those interested in Down syndrome and create an optimistic outlook and attitude. The editors reserve all rights.



## Self-Advocates Speak Through VATTA

Kirk Crowther, Acting Executive Director

This year the Voices at the Table Advocacy Committee (VATTA) celebrates its five year anniversary. Started in 2005 with twelve adults with Down syndrome from across Canada, the committee quickly proved itself to be the highest authority on issues relating to living with Down syndrome. The value of this group's contributions should not be overlooked.

In 2009, the committee's activities continued with advocacy opportunities in communities across Canada and around the world. Below we have included a few highlights of last year:

- Last year VATTA was the recipient of an Advocacy Award for their documentary film, Then and Now.
- The VATTA committee was present at the Affiliates in Action (AIA) Conference in Washington DC.

- VATTA was invited to speak at the World Down Syndrome Congress in Dublin Ireland, but politely declined due to travel costs.
- In 2009, VATTA was invited and participated at the National Child Rights Conference in Ottawa.
- To ensure that the group is advocating for another five years the committee has secured a funding commitment from **KPMG**. The committee would like to thank **KPMG** for believing in the work of VATTA and their impact on the citizens of Canada.

The committee meets this year in Regina, Saskatchewan at the CDSS National Conference. Future plans for the VATTA group include more community based presentations and recruiting new self-advocates to be part of the team. In 2010, look for the development of a book written for and by self-advocates. At CDSS, we are very proud of the accomplishments of this small group of dedicated and valued VATTA members; we couldn't advocate on behalf of all Canadians without their perspective and collective voice.

## Provincial Aid Cuts Hit Alberta and Saskatchewan

Andrew Brown, Marketing & Communications Manager

In recent months there have been ongoing reports of ever increasing provincial cuts to social services, including those that serve people with Down syndrome and their families.

In December of 2009, the Alberta Government announced that it will cut funding to organizations and eliminate critical services that provide imperative supports to vulnerable Albertans.

In February of 2010, the Saskatchewan Government outlined specific cuts to the education system, including a plan for special education students that proposes 75 per cent of educational assistant positions in Saskatchewan be eliminated within seven years.

The Ministry of Education sets out guidelines recommending school divisions hire more profes-

als, such as psychologists, speech-language pathologists, occupational therapists, and nurses. Some of these professionals work at several schools within the each school division.

The Canadian Down Syndrome Society works diligently to lobby public decision makers to ensure legislation made nationally and in provinces across the country are in the best interest of over 35,000 Canadians with Down syndrome and their families.

The Canadian Down Syndrome Society is gravely disappointed with these announced cuts and encourage all citizens to advocate for a favourable resolution that benefits all citizens with developmental disabilities.

Visit the "Media" page on the CDSS website ([www.cdss.ca](http://www.cdss.ca)) for more details.



Janet Charchuk, VATTA Member

# Learning Through the *Experience* of Others

by Ashlee Orr

*The Canadian Down Syndrome Society is pleased to introduce a much needed resource on breastfeeding babies with Down syndrome. This is how our journey began...*

Last January I found myself on the doorstep of the Canadian Down Syndrome Society (CDSS). I was a graduating social work student, eager to immerse myself in a new learning environment.

Kirk Crowther, Acting Executive Director, approached me, wondering if I was interested in initiating a research project on breastfeeding babies with Down syndrome. After six years of post-secondary education, I was confident my research skills were up to par. I accepted the offer with enthusiasm and curiosity. Although I am very knowledgeable about Down syndrome, I am not as familiar with breastfeeding, so I contacted a lactation consultant at the local hospital to get started.

The team at the CDSS agreed that it would be valuable to include narratives of parents in the brochure, describing their experience breastfeeding their baby with Down syndrome. I wrote a teaser in the January edition of 21 Monthly, encouraging parents to send us their stories. Much to our surprise, there was an overwhelming response. Within a week of releasing the email newsletter, my inbox was filling up with stories and quotations



from mothers across Canada. It became clear to me this was a topic of conversation that required further pursuit!

As I read through the submissions, a prevailing theme emerged – parents were repeatedly ill-informed that babies with Down syndrome don't breastfeed. Furthermore, information about breastfeeding babies with Down syndrome was very limited, often non-existent. It was at this point that I recognized the true value of this much needed resource.

Upon further reading, I noted many commonalities among the stories:

- ＊ Most hospital staff were not knowledgeable about breastfeeding babies with Down syndrome
- ＊ Mothers were not given adequate support from hospital staff in breastfeeding their baby
- ＊ Health complications at birth often delayed the breastfeeding process

With this being said, I also noted the perseverance that all of the parents had on their breastfeeding journey. Many parents visited their babies in the intensive care unit several times a day to ensure their baby received the nutrients of breast milk. Also, many mothers continued introducing their baby to the breast for several weeks

**“I saw a woman staring and smiling at me as I nursed Amanda through one of the sessions at the conference. After the session was over, the woman introduced herself as a community health nurse. She told me she had never met a mother who had successfully breastfed an infant with Down syndrome in her nursing practice.”**

– Karen Bartell, mother



before the baby properly latched on. One mother describes the first time her daughter latched on, after feeding from a bottle for over two months:

**“Bethany was getting fussy. The doors were all locked and the mechanical breast pump was inside, so I decided to offer her my breast once again. Much to my surprise, she latched on at once and nursed strongly, without the slightest dribbling! I was overwhelmed as my persistence paid off!”**

– Julia Flumerfelt,  
*mother*

These stories provided me with the inspiration to create the most accurate and up-to-date brochure possible. After talking with parents and health care professionals, it was evident that this resource was long over-due.

Over the next four months, I initiated meetings and telephone conversations with parents and professionals across Canada. Each individual had a different experience working with babies with Down syndrome, and all were eager to share their insight on the topic. After assembling the research findings, I filtered through the information and compiled a detailed document. The brochure is now in the editing process and is set to be published by the summer of 2010. I am thrilled to be a part of developing this much needed resource!



The Canadian Down Syndrome Society is excited to include this brochure in our New Parent Packages in the future. (Did you know that the CDSS distributed over 1500 New Parent Packages to families and health care professionals across Canada in 2009?) Without the generous support of the **Down Syndrome Association of Hamilton**, the printing of this brochure would not have been possible. We look forward to sharing this valuable resource with you in the coming months!

# Benefits of Breastfeeding

Breastfeeding an infant with Down syndrome is not only possible, but provides notable benefits to both mother and child.

- \* The unique nutrients in breast milk can boost a baby's immune system and protect against numerous auto-immune disorders.
- \* Breastfeeding can provide warmth and closeness. The physical contact helps create a special bond between a mother and her baby.
- \* The repetitive sucking action during breastfeeding strengthens a baby's lips, tongue and face. This serves as a stepping stone for future speech development!
- \* Breastfeeding is convenient! It is always available and contains all of the nutrients, calories, and fluids a baby needs.

**Remember:** Although breastfeeding your baby is recommended, it may not always be possible. In such situations, it is important to remember that it doesn't matter how your baby receives nutrients, just that he or she gets them. Visit your local lactation consultant, health nurse, or family physician to learn more about the feeding options that are available to you and your baby.

# The Writing is on the Wall

by Stephanie Mamayson, Membership Coordinator

For the last century, people with disabilities have been struggling for equality and fairness in all aspects of their lives. Parents fight to have their children included in regular schools and play on regular soccer teams, self advocates fight to have a place of their own and live an independent life, employers fight to have the right facilitation and supports in place so that anyone who is willing has the same opportunity to have a job and contribute.

Canada has made great strides in the last couple of decades in the field of advocacy and one brisk Thursday in March, we made the next big step. On March 11, 2010, Canada Ratified the United Nations Convention on the Rights of Persons with Disabilities and showed that we truly are a country that values equality by declaring people with disabilities as full citizens of Canada.

The Canadian Down Syndrome Society had the privilege to be among the many organizations across Canada present at the convention. We were a part of the discussions that lead to this momentous occasion and would like to congratulate the Canadian government for their commitment and solidifying their status as a world leader in the area of disability rights.

The ideas of the Convention are not necessarily new, rather they build on existing international human rights treaties and reaffirm that people with disabilities are entitled to the same basic human rights and fundamental freedoms guaranteed to all people, without discrimination. The agreement is a significant resource that should help increase awareness about the importance of protecting and promoting the rights of people with disabilities and ensuring that the right supports are in place for full and meaningful participation in society.

## Basic Ideas of the Convention

### **People with disabilities are free to make their own choices.**

Who better to make a decision about your own life than you? Only you would know what is best for you, so why take away those basic choices and freedoms from people with disabilities? They should be free to make their own choices and live their lives accordingly.

### **No one will be discriminated against.**

Discrimination is an unhealthy and destructive force. It is no longer accepted in society; this applies to all people.

### **People with disabilities have the same rights to be included in society as anyone else.**

Inclusion makes for a brighter, more vibrant and accepting society. People with disabilities have so much to offer the human family and should be included as such.

### **People with disabilities are to be respected for who they are.**

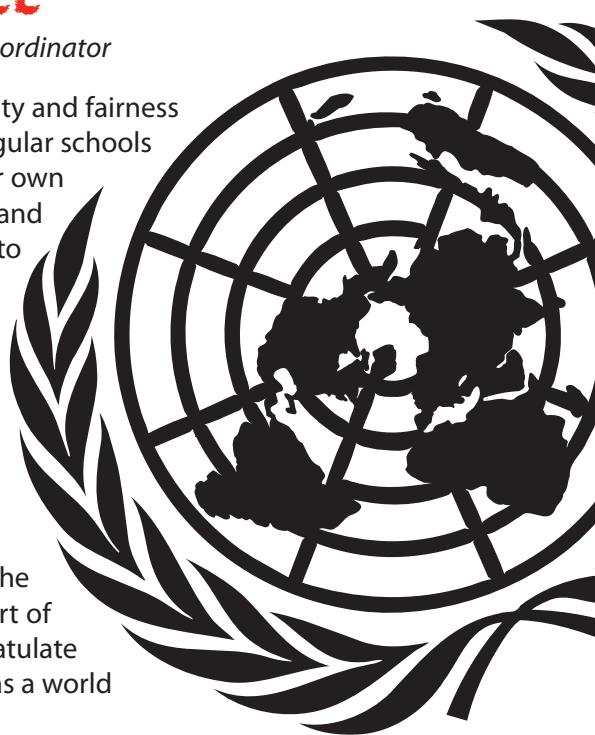
No one has the right to force someone to change who they are as a person. All people are unique and should be accepted as they are.

### **Everyone should have equal access to opportunities.**

Whether it's going to school, getting a job, or even just using a computer, people with disabilities should have access to the same opportunities as everyone else.

### **Children with disabilities should be respected for who they are as they grow up.**

People should be respected for who they are and that idea extends to the smallest and youngest members of society.



# Tying Your Own Shoes

by Chelsea Jones, CDSS Member

*Tying Your Own Shoes (2009) is a film that explores how it feels to be a little bit unusual. Directed by award-winning filmmaker Shira Avni, this animated documentary provides an intimate glimpse into the exceptional mindsets and emotional lives of four adult artists with Down syndrome. The documentary was created through a combination of interviews, artwork, and still frame animation.*

Huddled over the warm glow of a light box, three artists explain how they transfer their paintings to film, one brushstroke at a time. A blob of yellow is gently pushed across an illuminated piece of paper. Snap! Someone has taken a photo and the image appears on a nearby computer screen. It is the beginnings of a sun.

Through a series of workshops using light boxes and stop-motion animation over the last three years, these artists have come together under the direction of award-winning filmmaker Shira Avni to create *Tying Your Own Shoes* — a funny, poignant collection of intimate self portraits using new animation and interview techniques that haven't been seen in theatres before. Toting three awards so far, it's now cruising the international documentary film festival circuit on the heels of Avni's acclaimed film, *John and Michael*.

The artists — Matthew Brotherwood, Daninah Cummins, Katherine Newton, and Petra Tolley — will follow the film from Canada to the United States, taking questions from audienc-

es and teaching their techniques.

Avni and three of these artists spoke to freelance journalist Chelsea Jones about making their documentary.

## Where did this idea come from?

**Avni:** I can't really take credit for the idea. Matthew's father asked me whether I had ever thought of making a film where people with Down syndrome were a driving creative force behind the film.

## How did you get involved with this film?

**Brotherwood:** [Avni] approached me about this a few years ago because I've done art since elementary, and [been] into animation.

**Newton:** I was talked into it... [Avni] interested me in art.

**Cummins:** I got interviewed by [Avni] on a stage.

## Who played the lead role in developing the stories?

**Avni:** I had a set of basic interview questions that we had to toss because we would go off on tangents, and what they were saying was usually much more interesting than the interview questions that I had set up. So all of the content is their content.

## The film features everyone's art. How did you blend people's art with information from interviews?

**Brotherwood:** The art is like painting and colouring and going step by step; if you wanted to follow it you have to

watch this animation, you have to read bits, and then you have to picture it.

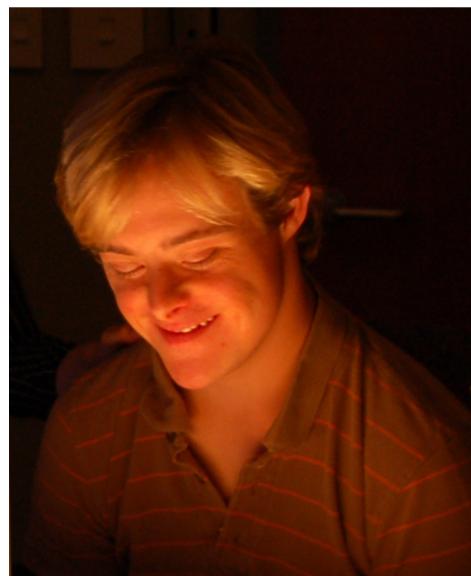
**Newton:** I like colouring... it's a grid and there's designs in it. It makes me feel good.

**Avni:** As much as possible, [the visual content] was based on the interview content. For example, the scene where Petra is talking about chromosomes, I played back what she had said the day before. I said, "This sounds really interesting, what do you imagine the chromosomes to look like?" So she animated what her chromosomes should be.

## What was the highlight of the film-making process for you?

**Brotherwood:** The best part is the interviewing [and] when they're asking questions about the animation.

**Cummins:** [Having] my name in a movie and Katherine and Matthew





and their names in the movie. I feel happy, I feel proud of myself.

### **With disability-based documentary being so specialized, how did you sell this idea?**

**Avni:** I was quite lucky; my producer was very open to it. I think just having had a measure of success with the previous film, *John and Michael*, opened up the programming committee to the possibility.

*John and Michael* is a love story between two men with Down syndrome and even Avni admitted it sounded like a very unlikely seller. The film has now earned countless critical acclaim.

### **Why did you choose to work with this group in particular?**

**Avni:** I thought it was really important to portray adults who are out in the working world... but also, I was quite concerned about the idea of informed consent. People needed to be comfortable with the interview process and verbal enough to engage with the interview process, which did cut off a percentage of the Down syndrome community: People who didn't go through the education system, or maybe grew up in institutions or grew up in an era where it was impossible to educate your child who has Down syndrome, [were] possibly less verbal. Even though their intelligence and possibilities are more or less the same as people who are more verbal in a younger generation.

### **What were some of the other obstacles in making this type of film?**

**Avni:** We had long conversations about sex and love and there's actually a lot in there that they asked me not to put in to the film because they felt it was too personal, and they didn't really want to share it with their families or their workers. It's just bad practice to take advantage of a population in the name of truth or of the importance of the film itself.

### **What is your perception of the disability-based film scene?**

**Avni:** There are really good films out there, but I think the problem is distribution. Often people think, 'Oh,

whose going to want to see that? That's such a niche market.' The other part of the problem is that often producers don't want to take a chance on having an actor [with a disability] if it's a fiction film, so they often pressure directors to hire non-disabled actors to play [these] characters and I think that does a huge disservice to the disability community.

### **What's your response to people who think disability-based documentary is a niche market?**

**Avni:** My response is that they should try it anyway and they may be surprised at their reaction.

### **What is the film's message?**

**Brotherwood:** It means [even if] you have disabilities, you have your own heart to show and [share] your art [with] people.

**Cummins:** Down syndrome makes me special. I like the movie so [much]. The movie was good. And everybody should watch [it].

**Avni:** I guess the message fundamentally is to keep an open mind and what you see is not always what you think. Someone with special needs may be much brighter than you think and much more capable than you think. [They may be] much more articulate, expressive, talented and capable than our initial assumptions. [People] just need to take the time to listen to them and get to know them more than we have been.

