



Calgary Down Syndrome Association

newsletter

JANUARY 2015

GETTING UP ON DOWN SYNDROME

CHILDREN'S CHRISTMAS PARTY | VALENTINE'S DANCE | WONDER YEARS CONFERENCE





GETTING UP ON DOWN SYNDROME
JANUARY 2015

*Getting Up on Down Syndrome is the newsletter of
Ups & Downs, Calgary Down Syndrome Association.
The newsletter is distributed to all current members
of the Association.*

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Children's Christmas Party

Sunday, December 14th

What a wonderful time everyone had at the Children's Christmas party. Santa and his reindeer arrived early with a bag full of presents for all the kids in attendance. Thank you Santa for making the special trip and knowing exactly what all the kids wanted!





Calgary Alberta Health Services

Respiratory Syncytial Virus is the leading cause of hospitalization due to lower respiratory tract infections in all children under 2 years of age. The aim of our program is to reduce the risk of developing a severe form of the disease in infants and children considered high risk i.e. Trisomy 21, premature infants, significant congenital heart disease.

Our program identifies children considered high risk for RSV illness and aims to reduce their risk by administering a medication called Synagis. Synagis is administered during the months of November through May when RSV illness is prevalent in Southern Alberta. It provides antibodies, which neutralize the RSV virus and is administered once a month by an injection into the leg muscle. Your child may receive up to six doses during the RSV season.

“The Alberta Respiratory Syncytial Virus (RSV) Prevention Program is a collaborative effort of the Northern and Southern Alberta RSV Prevention Programs to identify and coordinate RSV immunoprophylaxis for eligible infants and children residing in Alberta.

These programs are responsible for:

- Evaluating an infant or child’s eligibility to receive RSV immunoprophylaxis based on agreed upon criteria by the program directors in collaboration with invested parties.
- Notifying the referral source of the infant or child’s eligibility or non-eligibility.
- Coordinating shipment of palivizumab to regional points of care i.e. hospitals, community health centres.
- Connecting families to points of care where immunoprophylaxis is administered.”

A nurse from the RSV team will contact your family to review program information, address questions and receive consent for your child to participate in the RSV programs. Your child’s first appointment will be scheduled at one of our three Calgary locations or arranged at a clinic close to your residence.

If you have any questions please contact them at **403-955-3195**

All Children Can Soar

Renfrew offers a broad range of specialized programs and is an acknowledged leader in education for children with special needs and their typically developing peers. Our individualized programs and services help all children succeed.

Program Registration

Ongoing for the 2015/2016

- ECS Kindergarten & Junior Kindergarten

Ask about our

Integrated Services for Children with Motor Disabilities program

Assessment & Therapy Services

for children, adolescents and adults

- Psychological Services, Speech-Language Pathology, Occupational Therapy & Physical Therapy
- Easy to access - we can help you right now! Available year-round

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The Secret Thoughts on Acceptance

Written by: Krista Ewert

<http://www.kristaewert.com>

Most days, parenting Ella is just like parenting a typical child... except when it is not.

Today, was Ella's last day of soccer for the fall season and today was the first time that a girl was nasty to her. I suppose it wasn't a big deal. She simply exclaimed loudly that, "Having Ella out on the field won't do anything."

The 5 year old inside me wanted to yell back, "Like you do anything!?"

A bit later the same girl grimaced and backed away dramatically from Ella, when Ella made an attempt to join in their sideline fun. I had had enough and finally went up to her and reprimanded her for her behavior by simply saying that she was being mean and should be nicer to Ella. I realized completely after the fact that some parents might be upset with my initiative but the reality is, Ella isn't going to stick up for herself. In fact, quite the opposite. It was heart breaking to watch Ella on the field tonight. She was discouraged, and her lip popped out and quivered when she was cut out of play by meangirl and her friend (they were playing 3 on 3). As an isolated scenario, again, I realize it's not that bad, but in my mind, it is just a foretaste of what's to come.

Up until now, children have always been fairly kind to Ella. Curious - yes, mean - no. But I know that as the gap widens between Ella and her peers there will be many more situations in which Ella will be left out, made fun of and ridiculed. It breaks my heart. The irony of it is, is that later in the evening, I watched as a girl on the opposite team, fell and hurt herself. Only Ella, out of all the girls on the field, only Ella went up to her, and started to pat her back in an attempt to comfort her.

In so many ways, Ella is on par with her peers. For example, socially. In some ways, she is beyond them, like in showing empathy. And yet in other ways... many ways, she is noticeably far behind.

As we get further into the school year I am becoming more aware of the little parts of Ella's personality that are... what shall we say?... not so "normal."

It is easy for me to say that Ella is more the same than different when I am there to interpret, help and guide but when I am not there, I suppose I am afraid her "disability" will be exposed for what it really is. (I recognize how ridiculous that sounds). The children in Ella's class have been so accepting of her. They play with her at school and ask to have playdates with her outside of school. I could not be more thrilled that she is making friends...but...

But many of the friends ask if Ella can come over to their house. Immediately, my chest gets tight and I start to sweat. It is an entirely different situation if a friend comes to our house when I am home, and Ella is at home, and she knows her boundaries, but send her to someone else's house? A house I have never been to? With adults I have barely conversed with?

What if she has to go poo?

What if she runs away?

What if she tests the boundaries and wrecks something?

What if they can't understand my girl who I always say is so understandable?

We are stepping out. Our sphere is widening and while there are so many good things about it, while, I love to watch Ella warm the hearts of everyone she meets and make friends with those that have a chance to really get to know her there is part of me that wants to shield her from the meangirls of life and live in the ignorance of her disability where I can make it only what I can bear because nobody else really needs to come face to face with it. I want to shelter her from all the bad things people will say, the dirty looks and the whispers behind her back. But if I did, I know I would be also keeping her from the good things in life like friends who love her for her, disability and all.

Canadian Down Syndrome Conference

May 15 - 17, 2015 in Edmonton!

The Canadian Down Syndrome Society is proud to announce Spencer West, activist, author, and renowned inspirational speaker will be joining us as Keynote speaker at the 2015 Canadian Down Syndrome Conference in Edmonton. The Canadian Down Syndrome Conference celebrates people with Down syndrome, their families, and professionals in the Down syndrome community.

Inspirational and charismatic, Spencer West is candid about the struggles he overcame after losing his legs at the age of five. Whether headlining corporate conferences, filling stadiums, or leading volunteer excursions for youth and adults in Kenya, Ghana and India, Spencer's words have encouraged millions to stand up to difficult times, face challenges, embrace change, and learn the tangible skills each one of us can use to redefine what is possible both for organizations and individuals.

His many accomplishments, played out on the global stage, led him to teach others to redefine what is possible in their own lives.

Spencer's inspirational life story will help us kick off our great conference weekend. More exciting announcements regarding speakers, registration, and panels will be made at www.downsyndromeconference.ca soon!

Job Description for Ups and Downs Ambassador

- As an ambassador you will represent Ups and Downs at special events, speaking engagements, and in the media.
- As an ambassador, you are helping Ups and Downs raise funds and awareness so that we can continue to provide a future where all individuals are accepted.
- As an ambassador you will inspire people by sharing your story.
- As an ambassador you will help us thank donors for their support.

Events

- Serve as a guest speaker to share your story.
- Special jobs, such as working in a specific area.
- Meeting guests and thanking them for supporting Ups and Downs.

Media

- Sharing your story for print, radio or TV.
- Helping us promote an Ups and Downs fundraiser.
- Our donors and volunteers love to hear your story!
- People love to know how their support is making an impact.
- Being an Ambassador is a great opportunity to give back to Ups and Downs.
- Being an Ambassador builds your confidence and teaches you leadership skills

**STREET
MEET**

Celebrating and Supporting
Down Syndrome

Join the Street Meet Committee

We are pleased to announce the date of our next Street Meet: June 13. If you are interested in volunteering or joining the Street Meet Committee, please send an email to director@upsdowns.org for more information.

Ups & Downs

Calgary Down Syndrome Association is looking for a Treasurer

Board Descriptions – Treasurer

Term

- The Treasurer shall be elected from among the Directors at the first meeting following the Annual General Meeting.
(Bylaws – Article VI, A amended)
- The Treasurer serves on the Board for a maximum of one term consisting of 2 years.
(Bylaw – Article V a, 10 amended)

Responsibilities

- Carries out the responsibilities of a member on the Board of Directors.
- Attends Board meetings.
- Maintains all cash accounts
- Main contact for all deposits.
- The Treasurer's signature should appear on all cheques of the organization with the second signature from one of the remaining signing authorities (either the board or staff).
- Completion of Financial Reporting.
- Provide quarterly income statement report, budget vs. actual to the board.
 1. Q1 (quarter ended March 31)
– presented at June Board Meeting
 2. Q2 (quarter ended June 30)
– presented at August Board Meeting
 3. Q3 (quarter ended Sept 30)
– presented at November Board Meeting

4. Q4 (quarter ended Dec 31)
– presented at February Board Meeting
5. Year End as of Dec 31
– presented at March/April AGM together with statement reviewed by the Accountant

- Financial records are properly kept.
- Financial records are available to the Directors as directed by the Board.
- A qualified auditor audits the books and financial record of the association at least once each year.
- A properly audited statement is submitted to the Annual Meeting.
*At this time we do not do a completed formal audit, but we do a review every year.
- Make sure that legal and financial reports are properly filed on time. (ie. Casino report, government registration and charity return)
- Submit books and necessary materials to the Accountant for review of the financial position for the year.
- Completion of Casino report for the Alberta Gaming and Liquor Commission
- Assists in all organization's major fundraisers and events.
- Adheres to the signed Oath of Confidentiality pertaining to the Board and Association members.
- Orients the new Treasurer.

Approximate time commitment per month:
5 – 10 hours

Upcoming Events for 2015 | *Dates for Your Diary*

January 25
Vecova Swim Time

February 6
Dad's Night Out

February 7
Valentine's Dance

Postponed until fall
Wonder Years Conference

March 20-22
William Watson Lodge

April 19
Vecova Swim Time

April 25
Teen & Young Adult Conference

May 6
Annual General Meeting

May 8
1st Annual Mom's Night Out

June 5
Dad's Night Out

June 13
Street Meet

September 12
Ol' MacDonald's Resort

September 16
Charity Golf Classic

September 18-20
Easter Seals Camp Horizon weekend

October 24
Halloween Dance

November 6
Family Dinner & Dance

December 13
Children's Christmas Party

Get Social!

Join the conversation online and get the latest updates by following our Facebook and Twitter channels.



www.facebook.com/upsanddownscalgary



www.twitter.com/upsdownscalgary

Membership

Continue to support Ups and Downs by renewing your membership at www.upsdowns.org

Remember, your Ups & Downs membership comes with a variety of benefits and privileges including:

- Receive a bi-monthly copy of our newsletter
- Free advertising in our newsletter
- Receive invitations to attend all of our events
- Enjoy reduced, member rates for event tickets
- Access to members-only events
- Apply for Ups and Downs grant money
- Borrow items from our resource and toy lending library
- Receive free tickets to local events via Kids Up Front

Memberships are valid for one full year from the date of purchase or renewal. If you are unsure about your membership status, please email director@upsdowns.org

Share your story

We invite you to share with us your stories about Down syndrome. We would like to hear from parents, as well as children, teens and adults who themselves have Down syndrome. Your thoughts may provide the encouragement and support someone else needs.

Share your news with us

Do you have any news you'd like to share with other Ups and Downs members? Or, perhaps you have an exciting idea for an upcoming issue of Getting Up on Down Syndrome? Feel free to share your contributions by emailing us at director@upsdowns.org

Please note that event dates may be subject to change and you are advised to consult the website for the most up-to-date details

For further details on any of the events listed or to register, please visit www.upsdowns.org or call (403) 289-4394

Contact Information: If you contact information has recently changed please give us a call at (403) 289-4394 so we can update your information.