

Canadian Association for Williams Syndrome



CAWS Dream Maker

Well it has been a busy summer and back to school! I hope everyone has transitioned into their regular school and work routines.

CAWS had a conference call meeting on August 21st and at that meeting, I am really excited to share that we voted that Ottawa will be the location for the 2009 CAWS Family conference. We will be printing more information in upcoming newsletter on our website. We are also looking into making the same week, Williams Syndrome National Awareness week. Having just recently visited Ottawa, where we had a fabulous time, I know that the family conference will be a great time for every attendee.

I have some exciting news this newsletter to share with everyone! Eric went for his annual physical and there was a student doctor with Eric's paediatrician, Dr. Pion Kao. Dr Kao told me not to let him know Eric's diagnosis and he would research the symptoms. He guessed the diagnosis right away as he had just shadowed a paediatric cardiologist. After the appointment Dr. Kao's partner, Dr. Leong, came in and asked if they could do a write up on Eric and Williams syndrome in the National Paediatrics magazine. This certainly will raise a greater awareness of WS as every paediatrician receives this newsletter.

They took Eric's picture, which was a bit difficult because they did not want him to smile and he loves getting his picture taken - I am sure you can all relate to this. The chances of the article being published are positive, as Dr. Leong and Dr. Kao are professors of the University of Calgary. I will be informed and will receive the article if it is published to submit to our newsletter. Let us all cross our fingers.

We are very excited about our new fundraising idea, *CAWS Dream Makers* that Diane Reid has created. Please give generously so that we may continue to support research into the educational, behavioural, social and medical aspects of Williams syndrome, increase society's awareness of CAWS so individuals with Williams syndrome and their families have a resource available to them, become visible to the medical scientific, educational and professional communities by providing information on Williams syndrome and connect our families. If anyone else has some great fundraising ideas that could help with our conference please contact us! We want to ensure that the 2008 CAWS Family Conference is a huge success.

You will also read some repeats of invitations in this issue from our summer newsletter. We want our youth to have a voice for our families.

Inside this Issue...

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We have a Youth Correspondent who has not received a contribution for this newsletter ... there must be a "school or friend story" that you would like to share with our readers or a cool picture you have taken! We really want to include our youth in our newsletter, please encourage your children and youth to send a story or a picture.

At our June AGM, all directors and provincial contacts agreed that we could bump up networkith with our CAWS families by beginning regular e-information mailings but we need your email addresses. More information can be found in this issue. And a reminder, our next issue will have the

call for our annual music camp sponsorship, so start making that video. Remember, this is a great way to showcase your talent and make some new friends!

As our next issue will not be published until early 2008, I encourage each and every one of you to consider making a donation to CAWS Dream Maker fundraiser and we would like to wish everyone a great holiday season and hope the New Year brings health and happiness to all!

Jaimie & Gregg Tinling
CAWS Co- Chairs

Become a
CAWS
Dream
Maker

Please give generously.



Help us with our national fundraisers !
Thank you for your support!

CAWS Family Conference

Mark your calendars!

July 31 - August 2, 2009

Ottawa, Ontario

More information to follow in next issue

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Yukon/N.W.T.

Position Vacant
Volunteer required

If you would like to find out more about the role of a Provincial Contact
please call Gregg or Jaimie Tinling
If you would like to volunteer in your province, call your Provincial contact person.

MANITOBA

Our Kids

I just received a copy of the summer newsletter and wanted to thank everyone involved.

Also, a reminder to everyone who has the good fortune of having been blessed with a child who has Williams syndrome and may not realize it yet.

Granted, it is a bit tough at first, but once they get a little older they really start to shine in their own way.

I can't speak for all the kids but I know my daughter really keeps me grounded. Humility is her strong point. She really tells it like it is!

I am a firm believer that God created us exactly to specifications. He sure knew what he was doing when he created these kids. We should never forget to thank Him.

God Bless
Andy Cournoyer
Lorette, MB

QUEBEC

Our Teenagers

My name is Anne and I have a son who is 13 years old and has W.S.

My question to you is there any way I can get information from published reports or anywhere else that can help me with premature puberty. We are going through a tough time right now and I am not sure how to handle him. His body is developing faster than he is and he is have a hard time controlling his urges.

It would be very appreciated if you could mail me or e-mail me any information.

I will be waiting for your reply.

Thanks,
Anne.

Anne Villeneuve
7 Mayhew Road
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1-819-684-1066

ALBERTA

Our Adults

I have a 35 year old son with WS. He was diagnosed at age 6. He lived at home until he was 17 years old.

Because of his father's death, he then moved into a group home that had 4 other developmentally challenged adults. I applied to the courts and become his guardian and trustee prior to his 18th birthday. I remain in both roles to this day. Since then, he has lived in another group home, again with other clients and cared for by staff; a private residence, shared with another client (they shared a supportive roommate); to a rental property, with only a supportive roommate; and now to his own home, with a supportive roommate.

While in the rental property, the supportive roommate approached me on two occasions to grant permission for family members to live with them for various lengths of time. I agreed to grant the request and nothing untoward happened, of which I'm aware. The problem I am faced with now, as his guardian, is a third request from this same supportive roommate to accommodate a minor child without the mother's permission.

As a guardian, I have the right to say yes or no. Or I can say yes, but with conditions. I chose the latter and gave a period of 7 weeks for other arrangements to be made for the minor child. The supportive roommate has now decided to raise this minor child herself and wants to do so in my son's home. I have denied that request. She has now submitted her resignation as my son's supportive roommate. The dilemma I have now is that my daughter and I totally disagree on whether or not it is in the best interest of our WS adult to have roommates, in addition to his supportive roommate, rotating through his house staying for varying lengths of time. I strongly believe he needs structure, limits, and routines in order to achieve his full potential. I believe his home should remain the one constant in his life. Many different staff will come and go over the next few years; both at work, and at the agency we deal with. Supportive roommates will come and go as well, as their lives evolve and change. I believe my son should have a stable home that is a sanctuary for the rest of his life.

I would love to hear from anyone with a similar experience. Please contact me at foxymom@telus.net

News from Lisa Walsh

It's been an exciting year! In the picture I'm being taped by journalist Susan Bell from the CBC Radio show "The Current". Susan's on the left and on the right is my voice teacher, Irene Feher. Susan approached me in March to do a documentary about my singing.

She became interested in my story after she saw me in a TV documentary for the science journal show called – Découverte - which aired February 18, 2007 on Radio-Canada, entitled: Syndrôme de Williams. My involvement in that TV documentary happened when Dr. Daniel Levitin, a neuro-scientist from McGill University, invited me to be filmed for the show which featured his work on music and the brain. The TV crew from Découverte were a lot of fun. They filmed me in Dr. Levitin's Lab at McGill, at my work – singing at a fundraising dinner, as well as working at a nursing home. They also introduced me to a lovely Montreal jazz personality named Karen Young. I went to meet her at her home and the cameras watched as we got to know one another and did some accapella jazz improvisations. We had a great time and I was really proud when I saw myself on television.

Getting back to Susan Bell and the radio show - "A Born Performer" - which aired on the CBC radio show "The Current" on April 6, 2007 (re-broadcast in August). Susan came to our house several times to interview both me and my Mom. I really liked

the way she told my story, using my favourite song "What a Wonderful World". She also was able to use some of the material from the Découverte segment when I sang with Karen Young. I felt so proud when people from my community called to congratulate me after they heard the show. I also received some wonderful e-mails from people across Canada.

Well, that's not the end of my story! I also filmed another segment with Dr. Levitin for a British film company that was working on a project for National Geographic about The Brain. I again went to Dr. Levitin's lab; this time they asked me to sing with him – he is a great saxophone player. Watch for this show which is scheduled to air in February 2008.

My final filming experience this year was for the show "The Nature of Things" (CBC). In January 2008 this show will air four segments about "The Senses". Dr. Levitin's work and my singing will be featured in the segment about "Hearing". At the end of June I went to the CBC studio to record "Amazing Grace with Dr. Levitin and a beautiful, young jazz singer named Diane Nalini. The following day, Canada Day, the film crew came out to my house to interview me and film Mom and me making muffins.

I hope you will be able to see these shows. Thanks Mom, for helping me write about my adventures.





**CAWS is in need of a serious fundraising drive.
Our financial efforts require a new kick start so we will be able to:**

- ★keep producing a newsletter in mailout form
- ★keep our webmaster and webpage up to date
- ★ keep supporting families by phone calls, mailouts, etc.
- ★keep printing our brochures, letterhead etc.
- ★hold conference calls for meetings to generate an active
volunteer provincial contacts
- ★Host the 2009 Family Conference in Ottawa
- ★Continue to host a CAWS Family Conference every 4-5 years

Some thought has been given and we are hoping that YOU will think seriously about contributing. We are looking for family, individuals and corporate sponsorship donations. We would also like to share your stories and pictures of why you decided to become a dream maker of CAWS!

***We hope you will choose to become a member of
“CAWS Dream Makers”!***

To kick start this fundraiser, Jim and Diane Reid have decided to become part of CAWS Dream Makers by pledging \$2000 in celebration of their daughter, Jodi, who recently celebrated her 2nd anniversary of living in her own condo with very little supports. Jodi continues to amaze them with her determined efforts become the independent young adult she is today.

Canadian Association for

Williams
Syndrome



Dream Maker

We would like to help make dreams come true by committing to a

CAWS Dream Maker Level of _____ for a total of \$ _____

☐ In celebration of or ☐ In memory of

(please submit your story separately with photos if possible and elaboration of the occasion)

DATE

NAME

PHONE #











Address: _____

Email: _____


















DREAM MAKER LEVELS OF SPONSORSHIP

CORPORATE Dream Maker

Level	Dollar Amount	Offers to Corporate Sponsor
PLATINUM	\$3000 & Up	 Logo on CAWS national banner  Corporate banner to be displayed during Conference(banner to be supplied by Dream Maker)  Full page advertisement in newsletter for 2 Years  Recognition on CAWS website for 2 years  Corporate Logo on Conference shirt 2009
Gold	\$2000 - \$2999	 Corporate banner to be displayed at CAWS events (Provincial and National) in 2009 (banner to be supplied by dream maker)  Recognition on CAWS website for 1 year  Award trophy for CAWS Canadian Idol (CAWS to supply trophy)
Silver	\$1000 - \$1999	 Advertisement in newsletters for 1 Year Recognition on CAWS website
Bronze	\$500 - \$1999	 Recognition on CAWS website

FAMILY Dream Maker

Level	Dollar Amount	Family Rewards
Platinum	\$2000 & Up	 \$1000 a year for 2 years  Recognition on website  Your story in newsletter (CAWS will help you to write your story)  Hotel room for 2009 Family Conference 3 nights (Conference room rate)
Gold	\$2500	 \$500 a year for 5 years  Recognition on CAWS website  Hotel room for 2009 Family Conference 1 night (Conference room rate)  Sponsor on Conference T-shirt
Silver	\$1000	 \$200 a year for 5 years  Your story in newsletter (we will help)  Recognition on CAWS website  Award Trophy for CAWS Canadian Idol (CAWS to provide trophy)
Bronze	\$500	 \$100 a year for 5 years  Your story in newsletter (we will help)  Recognition on CAWS website

To kick start CAWS Dream Makers, Jim and I have decided to pledge \$2000 as Platinum Family Dream Makers in celebration of our daughter Jodi, who recently celebrated her 2nd anniversary of living in her own condo with very little supports. Jodi continues to amaze us with her determined efforts to become the independent adult she is today.

THIS IS JODI'S STORY ABOUT HER CONDO.

"A couple of years ago I asked my Mom if I could maybe get my own place. She of course freaked but then her and Dad bought a condo in Edmonton where I helped to choose the type of condo that I might like to live in. We painted and moved some furniture and then I decided it was too overwhelming and could not do this. Again with encouragement from my mom and dad I was able to finally just do it. NOW..I am never moving out...I love it...and so does my cat Taffy. We have some help and support through Edmonton PDD and people come and visit and help me cook. I am able to do most of my own shopping for groceries, and some cooking – and yes my parents don't always think I eat enough but I also know some good restaurants for eating out.

My parents are very special and I thank them for giving me this opportunity – they live in Calgary and I sometimes take the Red Arrow to see them but they also come up and stay with me. I have friends who come to visit me too. Sometimes we watch movies, have meals but mostly just have fun. I think the Alberta Association for Community Living has helped this world to realize people like me can live in communities. They could help a lot more people but they don't always have the money to help everyone.

My dreams are that everyone with a disability should live where they want to but especially they should try to be independent because it is a great life!"

So as you can see this is a reason for us to celebrate and become part of CAWS Family Dream Makers and we hope you will seriously think about becoming a Dream Maker or maybe seek out Corporations to become CAWS Dream Makers!



Jodi & her family



Jodi & her friend since Grade 5



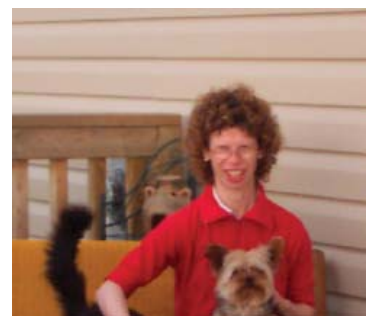
Jodi at WS camp



Jodi's little friend Flash



Girls just wanna have fun



Jodi and friends



Yum-Yum Auntie

E-Connections!

At our recent AGM, all directors and provincial contacts agreed that we could bump up our communication with all CAWS families, simply by beginning regular e-information mailings. This will in no way, replace our national newsletter but rather be an addition to the quarterly mailings.

SO, what do we need from you?
YOUR EMAIL ADDRESS PLEASE!

Please email your provincial contact with your email address so they can forward it on to our Co-Chairs who will build a national database in order to initiate these e-info mailings as soon as possible. ***Please also know that we will not share your information.*** And, if at any time you wish to be removed from this or another mailing, simply contact us by phone or mail at Gregg and Jaimie Tinling, 32 Cascade Place, Cochrane, AB T4C 1G6, (403)855-1115 (403)837-7408 or email: cawschairs@shaw.ca

Mark your calendars!
CAWS Family Conference
July 31 to August 2, 2009
Ottawa, Ontario

Pictures Wanted

We want to see your pictures...send us pictures of exciting happenings, or a special family picture or with one of your friends, a special trip, new braces - you name it!

We are reserving a very special page in the newsletter for YOU and your pictures. You can email them to Gloria Mahussier or mail them to 19 Pereverzoff Place, Prince Albert, SK S6X 1A8 and just write a sentence or two to describe what you are doing in the picture, your name, location and age!



CAWS Bulletin Board

You can post a question or share information with other CAWS families on our website.

Just send an email to cawschairs@shaw.ca with the words, "Bulletin Board" in the subject line. All questions and information sent in will be edited and reviews prior to posting. Please allow a week for your posting to appear.

WS on ABC news

Good Morning America had a segment in July called, "Cracking the Code of Happiness". You can watch the segment on the following link.
<http://abcnews.go.com/video/playerindex?id=3393673>

Law & Order

NBC's Law and Order SVU had a show with a child with WS on the episode.

You can view the video excerpt at the following link. http://www.nbc.com/Law_&_Order:_Special_Victims_Unit/video/#cat=new

Message from Youth Correspondent

We want to see your pictures and hear all your stories. I am sure that everyone has something to share. We would love to receive any drawings or poems. Please write to me - this one page is all yours!

Just remember, stories should be sent to me at samantha_healey@msn.com and be titled CAWS Youth Page and pictures should be sent to Gloria.

Samantha Healey
Youth Correspondent

New Disability Savings Option coming in 2008

Terry McBride, Special to The StarPhoenix, Saskatoon
Monday, September 24, 2007

The new Registered Disability Savings Plan (RDSP) will be available in 2008. The purpose of the RDSP is to help families improve the future financial security of their family member with a disability.

The family of a disabled person will soon get lots of help to save money. In fact, even if you don't actually have spare cash to sock away, the federal government might make some of the RDSP deposits for you.

A family with a low income (under \$37,178) can qualify for a Canada Disability Savings Bond (CDSB) of up to \$1,000. Such complimentary RDSP deposits are available each year for up to 20 years.

Canadians with family incomes under \$74,357 who deposit \$1,500 per year of their own money into the RDSP would see the federal government add a generous matching Canada Disability Savings Grant (CDSG) of \$3,500. Such matching government grants will be available until the end of the year the disabled beneficiary turns 49. By making regular deposits for 25 years you should be able to accumulate well over \$100,000 for your RDSP beneficiary. This nest egg could help pay for care for a financially dependent child after the parents have retired or died. The money can grow quickly because RDSP investment income is not taxable to the beneficiary until withdrawals begin.

Many parents will eagerly take advantage of the new CDSG grants. A large RDSP plus a sizeable life insurance policy on their lives should enhance the financial security for a disabled child. But what happens if the disabled child applies for social assistance at age 18? Will the RDSP be a help or a hindrance?

Social assistance programs have means tests. Entitlement to benefits depends on what you own and how much income you receive. Provinces try to limit support to those who are truly needy. Assets such as a house and a car are generally exempt assets. On the other hand, having a bank account is enough to disqualify someone from receiving social

assistance. Likewise receiving "income" in the form of a \$1,000 inheritance or winning a \$5,000 bingo prize could cause a person's welfare cheques to be cut off for a number of months.

Normally disabled welfare recipients face dollar-for-dollar clawbacks of their benefits whenever their families provide monetary support. Indeed welfare regulations seem to encourage non-monetary gifts.

The whole purpose of the new federal RDSP is to give families a way to provide monetary support to supplement provincial social assistance. Only the wealthiest Canadians would likely ever use RDSPs if such savings totally disqualify the disabled beneficiary from receiving provincial social assistance. Provinces are expected to revise welfare regulations to accommodate RDSPs. Ideally provinces would classify an RDSP as an exempt asset (like a house or a car) and significantly reduce the means-test clawback rate for cash received as RDSP withdrawals.

DISABILITY TAX CREDIT

If you have a disabled family member, you should help that person apply for the Disability Tax Credit (DTC), which is required to open an RDSP in 2008. Call the Canada Revenue Agency (CRA) at 1-800-959-8281 to obtain the application form. Alternatively visit the CRA website at www.cra.gc.ca to print form T2201 yourself.

Your doctor must verify that the person is "markedly restricted" in various activities of daily living to qualify for a DTC. Mail the completed T2201 to CRA.

The DTC is also the key to receiving the monthly Child Disability Benefit of up to \$195 per month for a child under 18. When a family member's DTC is transferred to a supporting person's income tax return, it is possible to save up to \$1,825 of tax per year (using Saskatchewan rates).

Because you normally have to wait for months to receive a reply on a DTC application, now is the time to get started.

Visit our website
CAWS-CAN.org

ADDRESS CHANGES

Please send your address changes and corrections to:

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fax: 306-922-3457
mahussier.m@sasktel.net

Happenings

November 10: Family Summit	Contact Family Voices Calgary at 403.717.0361
July 9-13, 2008	2008 - Dare to Dream The 2008 WSA National Convention will be held in Garden Grove, CA.
July 31 - August 2, 2009	CAWS Family Conference - Ottawa, Ontario

*What is happening in your province?
Give your Provincial Contact a call!*

COLUMN CONTRIBUTIONS

Please send your contributions for future newsletter features to :

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Fax: (306)922-3457
E-mail: mahussier.m@sasktel.net

Across the Country: A column to share with families events across the country and encourage parents to write about accomplishments their child or sibling has made in regards to the individual with WS. Achievements, no matter how great or small, can be enthusiastically shared!

Helpful Resources: Resources such as video tapes, computer software, games, books, etc., that parents or the family's interagencies have found to be helpful in assisting our children meet developmental milestones and achieve specific learning concepts.

Medical/Educational information: Articles concerning research and information pertaining to ongoing projects on medical and education issues.

Youth Voice: A page to place and share works by individuals with WS, be it an art sample, a photo, an essay, poem, stories, etc.

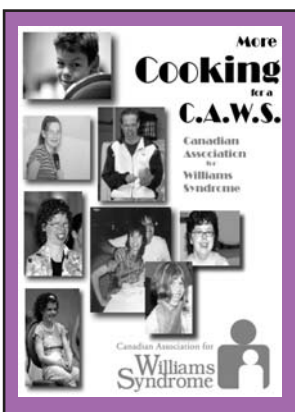
Website Bulletin Board: Ask a question or share information. Please forward your bulletin board contribution to cawschairs@shaw.ca with the words, "Bulletin Board" in the subject line of your email. Please allow one week for your posting to appear on the bulletin board. All questions to be posted will be edited and reviewed before posting.

CAWS newsletter is published quarterly. Due to limited space, we may not be able to print every item received. We report items of interest relating to WS and will provide a forum for other items of interest. CAWS does not promote or recommend any therapy, treatment, professional system, etc. We reserve the right to edit all material.

Visit our website
www.CAWS-CAN.org

NEXT SUBMISSION DEADLINE
January 15, 2008

Second Edition



**GREAT
GIFT !**

**ORDER
NOW**

THANK YOU

from the editor:

Thank you to Weyerhaeuser Canada, Prince Albert Division for the paper for this printing of the newsletter and to those that sent in contributions. The deadline for next issue is January 15, 2008. Gloria Mahussier

Your gifts are what keeps us active and operating. CAWS would like to gratefully thank individuals for their recent contributions. Thank you.

Employees and pensioners of Ontario Power Generation; United Way of Greater Toronto Employee donation from TD Canada Trust; via United Way of York Region, Alicia Mujica-Jaque of Amex Canada; Tim from via United Way of the Alberta Capital Region, Edmonton, AB; Regina St Croix via United Way of Avalon, St John's, NL; Francis & Beatrice Che, Edmonton, AB; Beverly Sochatsky, Edmonton, AB

In honor of their 50th wedding anniversary of Allan and Alma Kissner.
Happy Anniversary Allan & Alma! From Joyce & James Nargang

On the occasion of Brenda Scruton birthday Corrine Hingston of Calgary, ON

On the occasion of Alysia Roy's 14th birthday from Barbara & Gordon Kizuik of Clandeboye, MB

A tribute to Madeline Potier Stanley & Dorothy Lawrence of Oshawa, ON

In memory of Donna Eberhardt From Steve & Sheryl Toward, ON

In memory of Donna Schram. Many donations were made directly to CAWS and others were made at her celebration of life held July 18th, 2007. Sandra Bednarek of NewLowell, ON; Rosemond Jennett of Barrie, ON; Ethel Tomlin of Barrie, ON; Charlotte (friend); Prevett Family of Utopia, ON; Paul Schram of Orangeville, ON; Russ Rose & Tyler Schram of Barrie, ON; Don Renwicke of Utopia, ON; Charlene Pond & Fred of Waterdown, ON; Myra Forster & Leslie Gerrard of Angus, ON

DONATION FORM

Your gifts are what keeps us active and operating. CAWS would like to gratefully thank individuals for their recent contributions. Thank you.

DONATION FORM

Attached is my cheque payable to CAWS in the amount of:

☐ \$400

☐ \$100

☐ \$65

☐ \$35

☐ As a memorial to _____

☐ A tribute to _____

☐ On the occasion of _____
(Birthdays, Anniversary, Graduation, etc.)

Donations to the Canadian Association for Williams Syndrome are tax deductible. Canada Customs & Revenue Agency #879205516 RR001. All donations may be forwarded to: CAWS National Office, P.O. Box 2115, Vancouver, BC V6B 3T5 Thank you for your support!