

Northern Directions



Balancing Life's Tough Times™

Families of Spinal Muscular Atrophy Canada

1-800-866-0016

www.curesma.ca

It's On! Canadian SMA Conference—Montreal, Quebec

There was an overwhelming positive response to the conference survey conducted in the fall of 2005. Plans for the conference are currently underway. Mark your calendars for June 10, 11 and 12, 2006.

Details regarding the workshops and registration process will be announced in the coming weeks.

In the meantime, here are some things you can do to prepare:

1. Be sure FSMAC has your CORRECT e-mail address (quite a few e-mails are bouncing). Then you can be sure to receive updates about the conference and research news. E-mail Bettylou at bettylou@fsma.org to make sure your information is up-to-date.

2. E-mail Louise at louise@CureSMA.ca if you are interested in volunteering for any of the following:

- a. organization committee member
- b. hotel liaison
- c. registration desk volunteer
- d. workshop greeter
- e. breakfast or dinner host
- f. other

To host an event like this will take tremendous work from a team of FSMAC members and we need your help.

All questions and concerns regarding the conference can be directed to Bettylou or Louise.

FUNDRAISING CDS

FSMAC now has CDs available for fundraising purposes. These CDs have pictures and bios of people living with SMA. There is an international version with 81 pictures on it and a Canadian version with 30 pictures.

NOTE: We are always happy to get more pictures. Please send any pics or bios to Susi VanderWyk (Manitoba Head Office address) or by email to susi@curesma.ca.



Holiday of Hope Campaign

This holiday season Families of SMA launched their first mail-out fundraising campaign. The theme was "Holiday of Hope" and focused on the need for medical research donations. Almost 5,000 letters were sent out to previous donors enticing everyone to make a holiday donation to FSMAC.

We didn't end there. THANKS to the awesome generosity of Titan Outdoor Canada, 5 second and 15 second video clips of the Holiday of Hope campaign aired on the massive video screens in downtown Toronto, aiding in raising awareness of SMA and the need for donations.

Just look at the powerful image that was used to grab the attention of the campaign recipients! What an awesome face. Like so many kids with SMA, this little guy's eyes were powerful and

penetrating, reaching deep into one's soul.

We're pleased to announce that the 2005 Holiday of Hope campaign raised over \$4,500 For SMA!

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Editor's Comments sarah@curesma.ca

As always, time flies by way too fast. I had hoped to have a newsletter out before Christmas and now it's February! I apologize and thank you for your patience and understanding.

In truth, I've been busy: campaigning in the federal election. The good news is that I did manage to raise some awareness for SMA.

"Do you have kids?" is a common question. I've taken it on as an opportunity to speak about SMA and our ongoing quest for a cure. As a result

SMA was mentioned in two newspaper articles (the Ottawa Citizen mentioned that our son had died of spinal muscular atrophy). Not bad. I figure it was the least I could do, seeing as I couldn't get a newsletter out during that time period.

Now, I confess, I'm gearing up to run again...municipally this time and I'll continue raising awareness about SMA as I go. I have more time until the election (it's not till November) and I'm hoping to work all the newsletter's in to my busy schedule.

What I'm also excited about is

the chance to attend a conference in Canada on SMA. I'll be going as your trusty reporter and will be putting out a special section on the conference. So if you can't make it, don't worry, I'll do my best to give you the next best thing.

We'll also be running a profile newsletter on the research you donations fund. Giving you a glimpse into the lives of our Canadian researchers and the fight for a cure.

I have also made a goal to get out to one of an SMA runs some time soon. Maybe this will be the

year. I certainly encourage all of you to try and attend an event or fundraising activity in your area. Or better yet? Start one. We've some great suggestions this newsletter.

Remember to also consider shopandsupport.ca. It is a great opportunity to raise funds while doing your regular shopping or gift-giving. We'll be tracking its successes in each newsletter.

And remember: Please send in your stories, successes, or day-to-day challenges so we can continue to grow and expand our SMA community!

Never Give Up! – Part I, By Carol Wayland

My son Jared will be turning 18 next month. At birth he was a perfectly healthy baby. Growing up he played all sorts of sports and was very active. When he was 13, however, we noticed some mild tremors in his hands. After many tests, including a muscle biopsy, Jared was diagnosed with SMA Type III. I still remember the devastation we felt, so unsure of what was ahead. What would the future hold?

Within a few months Jared was noticeably weaker. We had to find ways to make life as easy and normal as possible for him. Jared had a few falls so he decided a cane would be good; a cool-looking one that helped make walking and standing safer. Climbing stairs became unsafe so we put an addition onto our house with many modifications, including an island in our kitchen with high stools as he can not get out of a regular chair anymore.

Since Jared still walks it is hard for him. Most things are either accessible or wheelchair accessible, so he falls in between. With little strength in his arms he can't get on a city bus, out of a car, and public toilets are a problem because they aren't high enough. The biggest challenge is going out when it's wet or snowy. He has trouble walking because he slips and has a problem regaining his balance. He misses a lot of school with this, though they are supportive: sending home work and providing extra aids.

It's been hard on our two other kids to watch him struggle. His brother who is 15 can help him a lot and they've gotten very close. My daughter has had a hard time with it; she was 5 when he was diagnosed and watched a fine healthy boy all of a sudden lose everything.

Jared doesn't let anything get in his way. He goes out all the time with his friends and is very

outgoing and personable. There are few people in St. Catharines who don't know him. He does have his down days but he has such a spirit he is a leader to everyone and actually helps us when we are down. Jared is planning on going to University this September to be a geography teacher.

SMA is a challenge but you have to keep focused and just keep looking until you find a solution to the issue. It's about making things as easy as possible. Jared doesn't go anywhere unless he thinks it out ahead of time. Even to go to one of his brother's hockey games he needs to consider the arena accessibility and whether the



The Wayland Family

sidewalks are clear.

All of our family, his teachers and friends wear SMA bracelets to show their support for Jared. Our kids' schools all give money from dress down days. Jared has a lot of support and he knows he is not alone. It's all about raising awareness. Jared is an inspiration and we're so proud of him.

Part II will be carried in our Spring Newsletter! You can reach Carol at : cwayland@sympatico.ca

Fundraising Ideas—Shop And Support with FSMAC

Do you ever shop at Sobeys? Petro Canada? Canadian Tire? Shopper's Drug Mart? Have you ever calculated your yearly grocery bill? Your gasoline bill? Your children's clothing bill?

On average families spend at least \$20,000 per year on these everyday items. By using the FSMA Shop & Support Fundraising Program, each and every family can contribute with no additional out-of-pocket expenses.

Now you can raise money for FSMAC every week by simply shopping using gift cards & certificates from over 80

brand name retailers that we all shop at.

FSMAC receives a percentage from each card & certificate purchased, ranging from 2 to 15 per cent.

They can be used as cash for just about any household purchase including food, clothing, entertainment, gasoline and even dining out. Everyone can participate—parents, neighbours, grandparents and local businesses.

It is so simple. Here are the steps:

1. Log on to www.shopandsupport.ca
2. Click on the JOIN box and create your personal profile. REMEMBER to type in Group ID #0100552630 (and verify it)



| DATE | Orders Placed | Funds Raised |
|--------------|---------------|---------------|
| Nov/2005 | 7 | \$69.75 |
| Dec/2005 | 3 | \$60.55 |
| TOTAL | 10 | 130.30 |

National Campaign Launch—Be An Angel

Moved?

Take a moment. Send in your address changes and help minimize mailing costs and maximize money for research!

Remember:

Memberships are a tax-deductible donation! Please help us reduce costs and mail in your membership form today!



The 'Be An Angel' Program started when Erich Feibel approached the Acton Sobeys looking for sponsorship for the Esso Rebecca Run for SMA (covered in the Winter 2005 issue of the newsletter). He generated a program that allowed store patrons to give donations at the cash register. In the past two years Erich's program has been a major success and raised over \$11,000.

With this success in mind, we have re-engineered the program to work for ALL FSMAC mem-

bers. Originally we had hoped to have numerous large companies run the program on a national basis, but they were already committed to many other charitable activities.

Well, we in the SMA world won't let that stop us. Erich didn't! And so the 'Be An Angel' program has begun.

This 'now available nation-wide program' is all about working with your local store. When checking out, the cashier asks customers if they'd like to 'Be An Angel' by buying a set of wings. The patrons make a donation; write their names on the wings which are then posted in the store window.

This is a great opportunity to generate awareness in your own cities and towns.

How can you get involved? It's really quite simple—just follow these instructions:

1. Order a 'Be An Angel' Program pack from louise@curesma.ca or 950-836-9121.
2. Read the package details carefully.
3. Visit your favorite store(s).
4. Ask them to run the 'Be An Angel' program.
5. Give them the 'Be An Angel Program—Store Pack (which you will have received from Louise).
6. Help choose the dates.
7. Watch the donations and awareness pour in.

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Our Mission

To fund the best possible Canadian research in search of a treatment or cure for the SMA diseases. To support families and individuals affected by SMA.

UPCOMING EVENTS

27 May 2006— Butterfly Dance in Bradford, Ontario. Contact Angie Wright at 905-775-0490 or angie@nof49.ca.

10,11,12 June 2006— Canadian SMA Conference in Montreal, Quebec. Volunteers needed, contact louise@curesma.ca.

8 July 2006 — 5th Annual Esso Rebecca Run For SMA in Newmarket, ON. For more information go to www.rebeccarun.com.

14,15 July 2006— FSMA Families and Professional Conference in San Diego, California. Check out www.fsma.org for more information.

21-27 July 2006— SMA Family Camping Trip at Cultus Lake, B.C. (10 minutes from Chilliwack). E-mail susi@curesma.ca

8 August 2006— Run, Walk & Roll for a Cure in Calgary, Alberta. Contact smacalgary@yahoo.ca for further details.

13 August 2006— Quinn's Quest for a Cure, Winnipeg, Manitoba. www.quinnsquestforacure.com

11 November 2006— Enjoy Dinner and a Dance in Milton, Ontario. Contact Theresa Van Fraassen at 519-853-9718 or vanfraassen@cogeco.ca for information.

In Memoriam

Michael Bristow

June 4, 2005 - December 27, 2005

Ontario



Mark Your Calendars— The Esso Rebecca Run is Coming Up and Is Five Years Strong!



Hayden Philip MacIntyre
2006 Race Honoree

After an incredible first 4 years, the Esso Rebecca Run for SMA Committee is pumped and ready to host an awesome 5th anniversary event this coming summer.

We're five years strong and so who could be a better choice to hold the position of Race Honoree than Hayden MacIntyre? With this being Hayden's 5th year participating in the events, he's a natural choice to lead the 2006 race to a cure and treatment for SMA.

Six-years-old, Hayden is an exceptionally bright and engaging boy who at 8 months of age was diagnosed with SMA Type I/II.

Already he has battled more obstacles than many of us have to deal with in a lifetime. Hayden will be joined, as usual, by his Mom and Dad (Ian and Tina) and his sister Lauren (age 3, unaffected by SMA).

Again there will be a 5km run/walk event, a 3km walk/roll

event and the 1km SMA Scamper for kids under the age of 2. This is always followed by the awesome free BBQ, the face painting, balloons, massage tables, the HUGE silent auction, awards and more.

With the organization in the early stages everyone is hoping to bring even greater awareness of SMA to the world and surpass the goals of raising a total of \$500,000.

Special thanks go out to all sponsors, particularly Imperial Oil and the Independent Esso Dealer Owners.

Although one of the goals of the Rebecca Run has always been for SMA families to be able to attend and enjoy each other's company without hav-

ing to do all the work, involvement is welcome from everyone. If you or your family members are interested in any of the following, please contact Race Director Louise Smith at louise@rebeccarun.com:

1. Corporate sponsor donations
2. Silent auction items
3. Donations for race bags
4. Draw prize donations
5. Volunteers for race day and/or committee positions

Everyone is looking forward to seeing old friends and making new ones on July 8th. Hope to see you there!