

Families of Spinal Muscular Atrophy Canada

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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

2 April 2005 — Auction/Dinner/Dance held in Chilliwack, B.C. Please call for details, 604-824-8999 or email susi@smacanada.com for more info.

23-25 June 2005 — Families of SMA Conference in Philadelphia, PA. See www.fsma.org for more info.

9 July 2005 — Rebecca Run For SMA held in Newmarket, ON. More information and to register go to www.rebeccarun.com

22-25 July 2005 — 6th Annual FSMAC

SMA CHARM

NEW this spring -SMA charms for your Italian charm bracelet.

This is a great opportunity to raise funds for FSMAC AND raise awareness about SMA at the same time. The double-link charms sell for \$15.00 each.

Order by contacting louise@SMACanada.com. These are so great - you can order one for yourself

Family Camping Trip. Located in beautiful B.C. at Cultus Lake everything is accessible and all inclusive for family fun. Contact Susi Vander Wyk at susi@smacanada.com for more info.

6 August 2005 — Calgary Run/Walk/Roll for SMA. For more information contact SMACalgary@yahoo.ca

14 August 2005 — Quinn's Quest for a Cure will held in Winnipeg, MB. For more info contact hunterorchar@aol.com

or a bunch to sell to your friends and family. Bracelets (Stainless Steel) are available as well. Shipping costs will apply.



Editorial Underpinnings

This issue is short and sweet. Mainly because we think it's more important to keep you in contact than it is to cram out a huge issue.

We're moving to four times a year. So please, submit information, memorials, upcoming events, anything. We need to stay in contact to keep information and awareness flowing.

This issue we're focusing on upcoming events and awareness raising, plus some fundraising ideas. I decided to profile some books as I know talking with our children about their special needs and about grief and loss is complicated. Hopefully some of these books

will help. And to add a little, why not purchase them through iGive.com?

Yes, I haven't forgotten knitting for a cure. The logo is designed and ready. An FSMAC afghan is in the works and will be ready (fingers crossed) by next issue. Sweaters to follow.

Please note upcoming events in your areas and plan on attending. Numbers alone can help raise awareness.

Next issue will be out (fingers crossed again) June 2005. Feel free to contact me through the head office or via email at samplonius@fsma.org.

Shopping Anyway?

Many of us now rely on and use the internet for basic everyday shopping. If you're looking for ways to give a little while you get a little (or a lot) consider shopping through an internet 'mall' like www.iGive.com.

iGive.com allows you to shop at a variety of American, Canadian or U.K. stores with a percentage of your purchases going to the charity or charities of your choice.

And yes, Families of SMA Canada is on that list.

This means that if you currently order from www.chapters.indigo.ca you can now go through

iGive's site and an automatic donation is given to the charity of your choice. Other Canadian companies? Canadian Tire and Roots.

A running tally of what you've raised for your cause (or causes) is kept at the top of your personal page. Donations vary by vendor but it's a good example of how doing a little can help a lot.

If 2% of your purchase goes to FSMAC, that means that your 40 dollar book purchase just raised 80 cents. Over the years that adds up. Give it a try. Give a little at iGive.com.



Families of SMA Canada

Winter 2005



Balancing Life's Tough Times™

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 for them. Please send any pics or bios to Susi Vander Wyk (Manitoba Head Office address) or by email to susi@smacanada.com.



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Northern Directions

Families of Spinal Muscular Atrophy Canada

1-800-866-0016

www.curesma.ca

Rebecca Run for SMA—2005



The organizing committee is hard at work making sure the Rebecca Run on July 9th is another stellar event. We are very excited that Imperial Oil has joined as the lead sponsor for the event, along with the Running Room.

This year will offer a 5 km run, a 3 km walk/roll and a 1 km SMA Scamper. The Scamper is free for kids under the age of 12.

Please plan to attend this event, you'll have an opportunity to meet and talk with many SMA families and children. Plus you'll get to enjoy the big BBQ, music, speeches, the massive Silent Auction and so much more. Christina McDonald will once again have angel wings available for the Angel Tree. You'll also get to learn about our Honourees, from Rebecca in 2002, Liam in 2003, Natalie in 2004 and now Abby and Jamie in 2005.

If you haven't made the trek to Newmarket yet for the Rebecca Run, you've been missing out on an incredible, inspirational, heart-warming event where we raise awareness about SMA.

Fairy Lake is a beautiful location for SMA families to meet and support each other. The Rebecca Run is a great opportunity to bring fami-



lies and friends to help in the quest for the cure.

If you'd like to volunteer or attend, please visit www.rebeccarun.com. We look forward to meeting you there.

If you live anywhere in Canada and you'd like to have a runner raise funds and run the Rebecca Run in honour or memory of your child, please send an email to louise@rebeccarun.com, asking to be included in the Running Buddy program.



In Memoriam—Jacob Daniel Proctor-Trick

August 20, 2003 - February 19, 2005

Some people never have the opportunity to see and angel, or simply don't look well enough to see them walking among us.

This however, is not the case for me. I, not only have seen an angel, I get to call him my son.

He is my 'Angel on Loan'.

Angela Trick



Books About Loss and Grieving



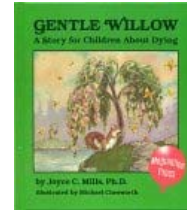
The Angel with the Golden Glow: A Family's Journey Through Loss and Healing

By Elissa Al-Chokhachy

A book for children, yes, but also for special children, and for big adults who have children who are different. The Angel with the Golden Glow is chosen by God to go to Earth and be born to parents and stay only for a short time. "You will be

born in this special earthly body. It will not work in the same way that most do."

Wide-sized pages with beautiful artwork and tender words create a vivid picture of sadness within an all-encompassing joy. Elissa Al-Chokhachy writes the way angels fly, and artist Graf paints like they smile. In love and in plentitude. For families who have loved and lost. For children who are born special. A rich panorama of grief resurrected. "Don't be sad, for there will be a day when we will be together again. And remember, I'll always love you, whether we are together or apart, one from the other."



Gentle Willow: A Story For Children About Dying, by Joyce C. Mills, PhD

This book was written for children who may not survive their illness. This comforting story will also help all children to deal with the death of friends, family members, or even pets. It is a loving and tender tale that addresses our feelings of sadness, love, disbelief, and anger. It provides children, and those who

read the story with them a "transformational" way of viewing death and dying. This profound story is ultimately one of joy and hope. Its message is one readers will not soon forget.

Other books to check out:

We Were Gonna Have A Baby. But We Had An Angel Instead, by Pat Schwiebert, ages 4-8

Little Tree: A Story For Children With Serious Medical Problems, by Joyce C. Mills, PhD

What On Earth Do You Do When Someone Dies?, by Trevor Romain, ages 9-12

35 Ways To Help a Grieving Child, The Dougy Center

Best Friends in Heaven – 2005 Rebecca Run Honourees



ABIGAIL LYNN LOEBACH
June 5–October 21, 2003

As we searched for our 2005 Rebecca Run honouree, it quickly became apparent that there was a very special story to be told about Abby and Jamie.

At the 2004 Rebecca Run, Abby's parents met Jamie's parents in person for the first time. It was incredible to see how their friendship formed immedi-

ately. These two sets of parents had much in common.

In the same year, after years of trying, both had given birth to beautiful baby girls. The babies seemed perfect at birth, and the eventual SMA diagnosis was a shock. The similarities for both sets of parents continued.

The Dr visits. The hospital stays. The endless pain of knowing what was to come. The wonderful love each felt for their baby.

When the parents met in person and shared their stories, everyone on the organizing committee instantly realized that up in heaven, these two little angels had created the opportunity for their parents to meet.

Knowing the girls are together, best friends in heaven, has helped Dave, Jennifer, Krista and Janne cope with their losses.

And so - it seems only fit-



JAMIE OLIVIA HAAPALAINEN
September 6, 2003 –
February 1, 2004

ting that we honour Abby and Jamie together, as these two special girls continue their work as angels, touching the lives of many.

To enjoy their full stories and watch their videos, please visit www.rebeccarun.com.



Rebecca Run for SMA

Fundraising Ideas

DONATIONS AT THE CASH REGISTER

Wondering how you can get the stores in your town to get involved with raising funds for FSMAC but you're not sure how?



In-Store Display

Why not approach them to do a 'donation at the cash register' program. We can supply you with the fol-

lowing items to make this work:

1. A proposal to give to the store – explaining how it would work.
2. Instructions for them to give to all staff members.
3. Angel wings to be hung in the store window.

This is a GREAT way of getting your community involved without the individual store having to spend big bucks. Shoppers will become aware of SMA, the store will be a part of the community and EVERYONE will be a part of medical history.

If you are interested in getting a 'donation at



Sample Window Display

the cash register' happening in your town or city, please contact louise@SMACanada.com

Take It To The Beach...

Moved?

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

If you have a family member with SMA, this may be what you've been looking for. A chance to hang out in beautiful British Columbia and share stories and good times with other families of SMA.

You are hereby cordially invited to join the 6th annual SMA family camping trip. Families from Western Canada as well as the United States attend. There is beach time, fishing, a wheelchair obstacle course, baseball and more. Everything is accessible and all inclusive for lots of



family fun. The best part is making new friends.

a lift. We will try our best to make it work for everyone.

Remember:

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



The dates planned are for July 22, 23, 24, 25th, 2005. Three nights in total. Held at the gorgeous area of Cultus Lake, BC. Bring your campers or tents, use the wheelchair accessible washroom equipped with

If you have needs you are concerned about, just contact Susi Vander Wyk at susi@smacanada.com or 604-824-8999 Check out the website at: http://web.mala.bc.ca/fucile/sma_camp/