

Northern Directions



FAMILIES OF SMA

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. Please send any pics or bios to Susi VanderWyk (Manitoba Head Office address) or by email to susi@curesma.ca.

Families of Spinal Muscular Atrophy Canada

1-800-866-0016

www.curesma.ca

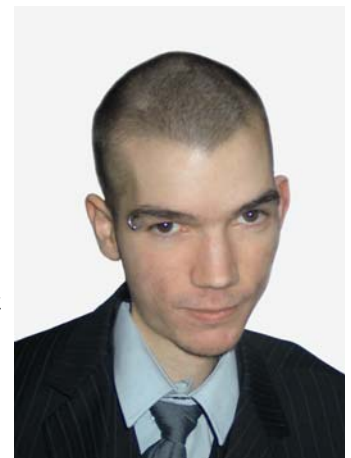
Mark McAllister—Defining Ability

Mark McAllister is no ordinary 22-year-old. He graduated college at the top of his class and snatched up a lucrative career in graphic design before he even *put on* his cap and gown. He ran for parliament (2005-2006) and is starting his own fundraising foundation. One could say he is constantly strategizing for his future and how to not only do more but also do it better than anyone else. Mark has SMA, but don't let that fool you.

Diagnosed at 11 months, Mark's parents were devastated with the news: their new baby would not live to see his second birthday. Thankfully in Mark's case that diagnosis proved false. Instead Mark was given another prognosis: Type II.

While Mark himself would characterize his childhood as rocky—ongoing bouts of pneumonia, surgery to have rods fused to his spine to

prevent curvature—one gets the sense that it was all handled with a steely resolve. As he commented in a recent news article, "I don't like to be seen as disabled, but rather someone with certain health problems who has been able to overcome a lot of things in life."



Mark McAllister

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Introducing The 2007 Rebecca Run Honoree



Every year we are touched by the many people we meet at the Rebecca Run. We have learned over the years that no two SMA stories are alike. We have also learned that all of us affected by this disease are

family. Yes, through a cruel twist of genetic fate, we have come together.

Meeting Scarlet and Boris Stefanovic was like finding a long-lost brother and sister. Although their SMA story is different from any we had previously heard, we felt instantly connected as

though their angel Sonja was working behind the scenes to bring us together. And so it is our great honor and privilege to introduce Sonja to all of you.

Louise Smith—Race Director, Rebecca Run for SMA

Sonja's SMA Story

By Boris and Scarlet Stefanovic

We waited 36 weeks and 4 days to say hello and all we got to say was goodbye. On January the 6th, 2006, the brief flash of life that was our baby girl, Sonja Natalia, was extinguished by a

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SMA Video Presentation by Louise Smith

The art of giving generally comes in one of three ways (or for some two or more).

For some it's easier and simpler to just give money. It's effortless (except for what it took to earn it in the first place) and is an easy and effective way to aid your favourite cause.

Some of us who do not have the funds to fork over for one reason or another (new roof or recently unemployed) often

choose to still support our charities by giving of our time. Volunteers are a crucial aspect of any charities survival and none would survive without the services of these giving individuals.

Lastly we can offer a combination of the above two and give a product or service. Some choose to donate an item from a charities wish list (either purchased new or pulled up from the depths of the basement

and dusted off). Others pull on their varied talents and skills and provide that which they do best.

FSMAC is lucky to have members who do all of the above.

In particular we'd like to take note of Dan Whalen. The loving uncle of a Type II niece, Dan took it upon himself in November of this past year to give of his time and service and created a powerful and meaningful video

presentation about SMA.

The presentation shows a full cycle of SMA. The dreadful and difficult loss of so many loved ones, the beauty of every SMA child and the hope for a cure that we all desperately cling to.

We at FSMAC are grateful for Dan's hard work and dedication to helping find a cure. You can view this presentation or download it promotional purposes at www.curesma.ca.

McAllister, cont'd

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And overcome he has.

Not letting SMA define who and what he would be Mark jumped straight from high school into Graphic Design at Cambrian College. While in hindsight he would caution those who have Type II (or any other progressive illness) to make plans that consider the long-term nature of their disease, the hard work and risks certainly paid off for him.

Mark was hired by 50 Carleton, Northern Ontario's largest marketing and advertising firm and has worked there for the past two years.

During college the only course he had to be exempted from was sculpture and that same dedication and perseverance has continued into his work life.

50 Carleton has set up an arrangement with Mark that permits him to work from home—keeping in contact via teleconferencing and the Internet.

"I can honestly say technology is the only reason I've been able to pursue a career in this field. I just wouldn't be able to handle the rigours of graphic design without the technological advances that have taken place over the past few years."

While pneumonia has contin-

"There comes a point where you would like to put aside the disabled part and be respected for your own skills."

ued to disrupt his life he continues to work hard. Having developed a reputation as a solid designer with a creative flair Mark has not had to worry that his lapses from work would cost him a job.

He continues to seek out excellence and strives to expand his horizons by considering further coursework. One of Mark's out-

side interests is the foundation he is setting up called the 2.0 Project.

This foundation will be a fund-raising and awareness-raising vehicle that's goal will be to put a human touch on the side of issues such as stem cell research and Mark's other interest—the life extension movement or transhumanism.

Mark's other passion is politics. He ran federally for the Green Party "on a whim" and because he is a strong supporter of environmental policies. He came out of it finding that he enjoyed the experience, enjoyed the debates and felt proud that he could offer a positive voice.

"I'm not one who typically speaks in front of a lot of people. I think I performed admirably. I gained the respect of my opponents."

Still, Mark is quick to point out that he ultimately "earned respect for doing what I did while being disabled. Sometimes this can work in your favour, where you get attention just for achieving something while being dis-

abled. But there comes a point where you would like to put aside the disabled part and be respected for your own skills."

If Mark had to point out the very thing he felt should earn him respect for his own skills—it's graduating college top of his class. He did not let his disability define him and ultimately 'out-classed' all his classmates. What set him apart there was not his disability but his abilities to be the best.

Nowadays Mark is setting his sights on the future. He is looking to expand his learning, build up his foundation, the 2.0 Project, and dreams of some day setting up his own design firm.

He doesn't discount politics as a path he will once again tread either though he states that he'll not run this term. Instead he will most likely volunteer—for the Liberals citing their support of individual freedom and personal liberty a big calling card for him. Some day he may even run for them, but not right now.

His parting words of advice for
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A Charity's Best Kept Secret by Darren Bray

As a charity, we are always looking at reducing our expenses and expanding on the number of ways that we can accept donations.

Now there is an organization that Canadian Charities have access to, which helps us accomplish both of the tasks mentioned above. CanadaHelps is a registered charity that exists to enable charities like ours to accept online donations at a minimal cost without compromising donor security.

Donors that would like the option of using their credit card should look to

CanadaHelps. Not only do you have the comfort of knowing your transaction will be handled with the highest security protection available, but also know that you have the flexibility of donating the amount you want, as often as you want. If it fits your budget better to make smaller monthly donations rather than a larger one time donation, you have that option. You can set up CanadaHelps to

automatically make a \$5 or \$10 donation each month. As CanadaHelps is a registered charity, you will be emailed a tax receipt almost immediately. It's that easy.

CanadaHelps also allows you to use your credit card to send a Charity Gift Card. It's a great way to send a gift to that friend or family member who has everything. In this age of consumerism sometimes it's better to give the gift of giving. You are reducing landfill from unwanted gifts and providing a special gift to those who really need it.

As the donor, you go online, choose the amount of the gift card, provide information about who to send the card to and CanadaHelps will email you a tax



receipt. Once the recipient receives the card by email they choose Families of SMA Canada as the recipient of the donation and the money is disbursed to our charity.

CanadaHelps facilitates over \$10 million in donations to Canadian charities annually and has been in existence since the year 2000. Its partners include

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Sonja's SMA Story cont'd

(Continued from page 1)

disease so insidious that none of the caregivers who had accompanied us on our journey suspected it was looming or even could recognize its mark.

For 35 minutes she fought for life but never cried, never opened her eyes. The baby we had dreamed of, the life we had anticipated was, in an instant, gone. For several months we waited for the report that would tell us why.

From the first day we suspected our baby was coming to us we were reluctant to believe our wishes had, after over five years, finally been answered. All around us family and friends were warmed by her spirit and glowed as they spoke with anticipation of the child that was so deeply wanted. It seems everyone whose life Sonja touched changed as she influenced the world around her in subtle ways; people became kinder, more patient, and more generous, to

each other and to us.

She reacted to the world around her, she responded to voices and foods and would dance and wiggle in the daytime to music her mother played for her and was considerate in sleeping through the night. Everything seemed to proceed normally and none suspected anything significant had changed when, at 26 weeks, Sonja performed an acrobatic shift in position and, thereafter, her movements gradually diminished; she was resting in a breach position. Although we were all blissfully unaware this point marked the beginning of Sonja's fight.

The following eight weeks were marked by rising blood pressure and a dangerous increase in amniotic fluid. Finally, with her mother's kidneys failing, Sonja was delivered by emergency caesarean section, the procedure made more diffi-

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Sonja Natalia Stefanovic

06.01.2006-06.01.2006

A Night To Remember by Theresa Van Fraassen



Theresa & Doug Van Fraassen

On Saturday, November 11th, 2006 the Glencairn Golf Club in Milton, ON hosted the Angel Gala for SMA.

There were 220 guests in attendance, including several SMA parents: Sue and Bob Motz, Scarlett and Boris Stefanovic, and Janet Genge and Joe Goicoechea.

We found the Glencairn Golf

Club to be the perfect venue and the staff did an outstanding job serving a wonderful prime rib and Yorkshire pudding dinner to such a large crowd.

While giving his eloquent grace Terence Whelan reminded everyone that we must never give up hope for finding a cure for SMA.

We had 190 items in our Silent Auction. There was something for almost everyone. A wide assortment of items was available ranging from children's toys to gorgeous gift baskets to art work. As well there was a multitude of sports memorabilia and tickets.

Ray Veene-man, a professional

auctioneer, donated his talents, and with his help we managed to raise \$11,000 in 11 minutes! The winning bidders left with the much coveted items: black pearls, a diamond necklace, platinum Toronto Maple Leaf tickets, a plasma television, and much much more.

After an electrifying speech by Louise Smith, Director of the Rebecca Run for SMA, the energy in the room was palpable. Once the dancing started, there was no stopping. The party continued well into the next morning.

In total we raised an incredible \$48,000.00. I would like to thank the SMA families



Louise & Paul Smith

who supported our event and all of our family, friends and neighbors who attended.

When planning the Angel Gala for SMA we set out to accomplish three things:

1. To raise awareness for SMA
2. To raise money for SMA; and
3. To throw a great party.

I think we succeeded on all three counts!



Scarlet & Boris Stefanovic



FSMAC T-shirts are \$15 and can be ordered from head office. Order forms are also on the website! Help fund a cure and promote SMA every time you wear it.. Sizes S-M-L-XL are available—call for availability of children's sizes.

EXTRA! EXTRA! EXTRA!

READ ALL ABOUT IT!

FSMAC OFFERS YOU A SNEAK PREVIEW OF....

“THE FACES OF SMA”

It's coming.....Soon FSMAC will be rolling out an exciting new fundraiser. Got email and internet? This one is for you! Won't take more than an hour or two to do but it will help find a cure for SMA. Keep your eyes and ears open. It'll be coming down the pipeline any day now. And now you can't say we didn't warn you.....

Fundraising Ideas—That Are Free! Yes, We Said Free!

Fundraising can seem an arduous task. Huge events like the Annual Rebecca Run may be beyond your current skills, time, etc. Granting a huge bequest or even 20 bucks can seem beyond your daily budget.

This doesn't mean, however, that you should give up until next year to consider making a charitable donation. For you can still help out.

Why? Because organizations like shopandsupport.ca, goodsearch.com, and igive.com provide those of us even on limited means to still give.

This year we're challenging all of you and ourselves to use the shopandsupport.ca website. We want to see 10 new members sign up and order. Our goal is to surpass \$1,000 in donations!

Though currently not a Canadian option, even easier is Goodsearch.com, which gives 1 cent from every search to your favourite charity. Right this minute you

could be giving 1 cent to FSMA (the U.S. affiliate). Seems silly right? I mean really what's a penny going to do. Well, to date FSMA has earned over \$1,640.61! It's possible that a penny a day could keep the doctor away.

Another website that allows you to give to FSMA Canada without actually giving is igive.com.

This simple site is a virtual shopping mall that allows you to do your regular online shopping while donating to your

favourite charity (and of course that is FSMAC). You can effortlessly donate up to 26% of the cost of your regular purchases by using this handy e-mall.

All of these sites provide users both young and old, rich and poor, the power to give without actually giving.

It may seem odd but it works. You CAN raise funds doing the things you do every day and it doesn't cost you a cent. Come on, how can you say no?

SHOPANDSUPPORT.CA	
TOTAL RAISED	\$368.35

Moving or Moved?

Take a moment to notify the head office—it helps us save on postage and frees up funds for research!

Remember:

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

Camping Call by Susi VanderWyk

Calling One! Calling All! The 8th Annual SMA family camping trip is on!

Once more it will be at Cultus Lake, B.C., which is near Chilliwack. Cultus Lake is beautiful and has the added advantage of an Elementary School where we camp with a wheelchair accessible playground and a lift equipped bathroom. It can also accommodate power hook up for kids using bi pap, etc.

There's a huge field for games

or just hanging out and baseball diamonds (for a family ball game). The beach, (as seen with docks) is a short walk away, as is miniature golf, waterslides, bumper boats, store, gas station, etc.

We can fish off the docks, go swimming, do crafts, play games, coordinate treasure hunts, undertake a champion marshmallow fight, and run an obstacle course made just for the wheelchairs and everyone else.

It is so much fun for the whole family, we just can't wait to see all the friends we've made in the past and make some new ones. Come on out, you won't regret you did!



The lazy days of summer....



CAUTION: KIDS AT PLAY

This year we'll be camping for 4 nights. Wednesday, August 22 to Sunday, August 26.

Cost for the property is \$10 per night per family, making it a very reasonable vacation.

Contact susi@curesma.ca if you have any questions, need directions or to make any other arrangements. See you there!

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.

CanadaHelps, cont'd

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Bell Canada, Bank of Montreal, CIBC, Hewlett Packard, RBC Financial Group, Ernst & Young, Microsoft and more.

Recently CanadaHelps added in a new option for personal donors called "Giving Pages". With minimal set-up donors can put together their own individual pages for weddings, fundraisers (such as the Angel Gala), birthdays, funerals or in memoriam pages. Pages can display a picture, a short description and then options to create links to one (or more) charities.

What an easy way to gather and direct donations.

This option is still in what they call the "beta" stage, which means it's being revamped with input from you. CanadaHelps encourages your input as they're relying on all of us to make this into the incredible service it can be.

Visit CanadaHelps today at www.canadahelps.org.

UPCOMING EVENTS

June 21-27, 2007—FSMA Family and Professional Conference Come to Chicago and make a family trip out of it. Check www.fsma.org for details.

7 July, 2007—6th Annual Rebecca Run! We'll be going strong at Fairy Lake in Newmarket, Ontario. Come on out and support the largest FSMAC fundraising run in Canada. Contact louise@rebeccarun.com for more information.

12 August 2007—Quinn's Quest For A Cure. Come on out to the 4th Annual race at Pineridge Hollow in Winnipeg.

22-26 August 2007—8th Annual SMA Family Camping SMA Family Camping will once again take place at Cultus Lake, B.C. For more information contact susi@curesma.ca

Northern Directions is edited by Sarah Samplinius. Any questions, comments and submissions can be sent to sarah@curesma.ca. We welcome your input.

McAllister, concluded

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those in high school dreaming of their own futures, are to plan ahead.

"In the future my disease will progress where what I am doing now will not be possible. It is important to plan ahead, 5 to 10 years ahead, be realistic and know that your disability will play a large part in your life."

But don't give up. Look at your skills, what you can and can't do and choose wisely. He looks wistfully at high school, wishing he had studied more and taken time to assess his own future.

"I was a better writer some would say and writing is more easily accommodated for a

disability. Safety wise that would have been a better choice."

It may have been a better choice. Maybe. But if you can choose one thing that you did well, did better than anyone and it shows your true ability, not just your disability, then maybe it was the right thing after all.

Mark stated in an article once that "I...feel it's the responsibility of every disabled person to make the best of the talents they do have and try and live their lives to its fullest potential."

Mark McAllister, you are doing that. Keep doing that.

You are an inspiration to us all.

Stefanovic, concluded

cult when it was discovered that several of her joints were conjuncted and unable to bend. Her mother had accumulated six times the normal amount of amniotic fluid and the loss of muscle tone that took Sonja's ability to swallow also prevented her lungs from developing, leaving urgent attempts at resuscitation futile.

Our beautiful baby daughter died because of SMA (Type I, onset in utero). This disease took her away from us but it will never take away the love we have for her or the joyful dreams for our lives together.

Sonja had an incredible spirit and desire to live, just like all the other people with SMA.

Even though she lived for only

a short time outside of her mother Sonja's love and spirit has touched many. We knew that Sonja was meant to be and that she had purpose in this world; her purpose and voice have outlived her little body.

Sonja's existence has helped to spread the word about SMA and will continue to do so. Information collected about her birth and from her autopsy will help in the research of this horrible killer. Sonja, like all the SMA angels, is part of our fight to help keep others from dying. She will do this by inspiring others to do their best to raise money for research and medical trials, spread awareness about SMA and fight the fight.