

# Northern Directions



FAMILIES OF SPINAL MUSCULAR ATROPHY CANADA

Fall, 2007

www.curesma.ca

## Finding Therapy on the Back of a Horse...



Bernie Ross—Horseback Riding

By Bettylou Ross

Over the years, we have tried and used many different forms of physiotherapy for Bernie (SMA type 2, born 1996, now 11 years old.) In fact, we are pretty intense about keeping him healthy and strong. He swims and stands every day, and these take up a fair bit of his free time – especially the swimming (he usually stands at school). As we only have Bernie at home, and we live out in the country, life can be pretty quiet (boring) around here.

So, I began to think that, as he's growing older, he needs some sort of organized physical activity that's more fun. (Okay, swimming IS fun, but not so much when you MUST do it every day. And we use a small indoor pool at home—so he's not getting out much with this activity.)

I investigated some ideas, including sledge hockey, power soccer, and horseback riding. There were also other sports that were suggested to us, including adaptive skiing, wheelchair basketball, and bocce, but we didn't investigate them.

Bernie didn't seem to like the sledge hockey when he tried it – our local team was supportive but mostly included paraplegics and other disabled kids who had good arm strength. Bernie needed someone to push him, and he didn't find the sledge that comfortable. It just didn't seem fun to him.

Power soccer seemed extremely cool but there was no team in our area, and it also seemed to be as all-consuming as being on a youth hockey team. We wanted something

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## Sixth Annual Rebecca Run

The sixth annual Rebecca Run, held on the magical date of 07-07-07, was a fabulous success—again. Record participants, record number of volunteers, and yet another record set in funds raised.

At press, \$158,000 was generated through the 2007 event held in Newmarket,

Ontario. This brings the six-year total to \$710,000 generated for treatment and cure research in Canada. An incredible amount indeed.

This success wouldn't be possible without the sponsors, participants, volunteers, and SMA families who contribute one way or another to this

amazing run.

Once again the event was buzzing with a 5km race for walkers and runners, a 3km walk/run/roll, and a 1km SMA scamper for kids under 12.

Throughout the event, MC

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### Of Interest:

- MOVING? TAKE A MOMENT TO NOTIFY HEAD OFFICE—IT HELPS US SAVE ON POSTAGE AND FREES UP FUNDS FOR RESEARCH!
- REMEMBER: MEMBERSHIPS ARE A TAX-DEDUCTIBLE DONATION!
- FSMAC NOW HAS FUND-RAISING CDS!

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# Northern Directions

## Taking the Teapot Hill Challenge!



Vander Wyk Family at the Bottom of Teapot Hill

“WITH THE AID OF THE C.R.I.S. VOLUNTEERS WE WERE ABLE TO GET TO THE TOP OF TEAPOT HILL...[WHERE] WE SUCCUMBED TO TEARS...OF JOY.”

The 7<sup>th</sup> annual SMA family camping trip is over for another year. We had a change of location this year. Instead of at our regular spot at Cultus Lake, B.C., this year's camping trip was held on the Vander Wyk's dairy farm. Regardless of the change, the kids had a ball. They rode horses, collected eggs, made bonfires, swam, made rockets, made ice cream, played board games and cards, and had scavenger hunts. They also made their own marshmallow shooter guns and had their own war! And, of course we also had our regular marshmallow war. Something nobody ever wants to miss out on.

For the camp this year, we had a Survivor theme, with family challenges every day. This year's winning family was the Barnes family from Ferndale, Washington, with a close second being the Cooke family from Chilliwack, B.C.

By far the most exciting thing we did this camping trip was having the Community Recreational Initiatives Society (C.R.I.S.) volunteers join us. C.R.I.S. offers outdoor pursuits for people with disabilities. Seven members came all the way from Kelowna, B.C. to volunteer their time to take our group kayaking and hiking with their specialized equipment and vast experience and knowledge. What an incredible time they showed us.

With the aid of the C.R.I.S. volunteers we were able to get to the top of Teapot Hill. Some of us were so overwhelmed when we got there and saw the incredible view we succumbed to tears. Tears of joy, of course, that we were able to share something like that with our children and each other. The volunteers enjoyed our group as well. They said that they would come again next year and do it all over again. It was so safe and a memory our

families will have forever.

At the end of our camping trip, we were tired, but had the time of our lives. We would like to thank the volunteers from C.R.I.S. for the adventures, as well as Ted Kawamura who shows up every year to donate his time and compassion to help make our camping trip so wonderful.

Tonight when putting my children to bed, Amy, my daughter, said she couldn't wait until next summer. I told her this one isn't over yet, why does she feel she wants it to be next summer? She said because then it will be the SMA camping trip again. I guess that says it all.

Next year the trip will be planned for the second half of July, please contact Susi VanderWyk if you are interested in joining us.

[susi@curesma.ca](mailto:susi@curesma.ca)

## Experience Outdoor Adventures in B.C.

Community Recreational Initiatives Society (CRIS) is a non-profit organization, based in the Okanagan Valley, B.C., offering various outdoor and wilderness programs to outdoor enthusiasts with disabilities.

CRIS offers a variety of programs for everyone—for the avid outdoor enthusiast keen on enjoying all the wilderness has to offer or the quiet placid type looking to enjoy a leisurely stroll in a local park. With short hourly strolls down park trails or a relaxing shoreline paddle, the types of experiences they offer are limited only by our societal boundaries.

Summitting mountain peaks, paddling pristine waterways, or hiking in remote areas are only some of the possibilities CRIS opens up. For more information check out their website at [www.coreinso.com](http://www.coreinso.com)



### Angel Gala — Milton, Ontario

The second annual angel gala will be held on November 17, 2007 in Milton, Ontario. Doors open at 5:30 p.m. with an opportunity to peruse the Silent Auction items and enjoy a cocktail reception.

Once again the event is being held at the spectacular Glencairn Golf Club and staff will begin serving dinner at 6:30 p.m. Following dessert a live auction will be held with the talented skills of

Auctioneer Ray Veeneman.

Of course, after that, the real party begins! Our DJ from Sound Sensation kept the dance floor hopping at last year's event and we are expecting a repeat performance!

During the course of the evening we will be having draws for door prizes and raffles. (We will be accepting cash or checks only for silent and live auction items).

Thanks to the generosity of last year's attendees, the Angel Gala already has raised \$52,500! That number can only climb as each annual event gets underway.

Come on out and help fund the research that will find a cure for SMA!

Tickets are \$100 each and can be obtained by contacting Theresa Van Fraasen at [vanfraasen@cogeco.ca](mailto:vanfraasen@cogeco.ca).



The Van Fraasens at last year's Angel Gala

### Therapy on the Back of a Horse, cont'd

*(Continued from page 1)*

fun, but we didn't have the energy and drive to start a local league and travel to play with other teams.

We then looked into horse-back riding. Bernie had tried riding ponies several times at fairs, but it had not worked well. Although he can sit quite well when placed, it doesn't take much to make him fall, so the swaying of the horse pretty much guaranteed that.

So it wasn't too surprising that he had previously seemed afraid of riding. Despite this, he was willing to give it a try. We weren't convinced, but we knew there was an excellent therapeutic riding center (Sunrise Therapeutic Riding Centre) only about 15 minutes away from our home, so we called and applied. It took about four months to get an opening.

I had expected them to use a

special supportive seat and was quite alarmed to see they intended to use an ordinary English saddle with volunteers on either side to support him. Also, he was not supposed to wear his regular back brace as it would probably bump the back of the saddle, and we wanted him to exercise his back muscles anyway – that was a main goal of the riding.

His first lesson didn't go easily as they had chosen a fairly tall horse, and the side walkers had a hard time reaching up to support him. And it was freezing that day – about -20, even in the arena. But Bernie loved it and was so proud!

The next week a smaller horse was used, and it was easier. The week after that they put a wide leather belt on him with handles for the side walkers to hold. Later on

we added a smaller back brace (not a custom-fitted brace but a simple six-inch wide Velcro belt that I had used when my back was bothering me.)

And so, each week went a bit better, and Bernie continued to love the lessons. The instructor would often have the students play games while on the horses – for example, trying to throw a light ball into a basket – to improve their balance.

At the end of the four-month session, Bernie had learned to sit and balance on the horse much better, though the side walkers still held on firmly. He also was helping to steer the horse with reins, though there was still a person leading the horse. Bernie had a real feeling of accomplishment, and he now looks forward to more day camps at Sunrise!

“AT THE END OF THE FOUR-MONTH SESSION...BERNIE WAS HELPING TO STEER THE HORSE WITH REINS...AND COULD HARDLY WAIT FOR SUMMER DAY CAMP AT SUNRISE!”



Sunrise is a registered charity that has been providing quality therapy, recreation, and life skills programs to children and adults with a wide range of special needs since 1982.

# Northern Directions

## Rebecca Run, cont'd



A race participant from Amsterdam, The Netherlands chats with a volunteer.

“NO ONE WILL EASILY FORGET THE INSPIRATION OF HEARING THE ENTIRE MASS OF PEOPLE CHANT: SONJA...SONJA... SONJA...IN MEMORY OF RACE HONOREE SONJA STEFANOVIC”

*(Continued from page 1)*

Chris Giles kept the crowd hopping. No one will easily forget the inspiration and motivation felt when Chris called upon the entire mass of people to stand still and shout our support to the spirit of Honoree Sonja Stefanovic. ‘Sonja...Sonja...Sonja.’

The massage tent was booming with free massages, stretching, gait analysis, and even acupuncture for those interested. The BBQ was bigger than ever thanks to the many donations of food and the stellar organization of Gail Pullin and Karen Purves.

Cathi Robinson, Director of the Silent Auction, sold over 180 items, everything from iPods to televisions—helping to generate significant funds for SMA.

As well, a special thanks goes to Directors Lesley Barclay and Leslie Summers, the free race bags were voted the Best In The World by the athletes in attendance.

And who can forget our

sponsors? We have over 130 sponsors for the Rebecca Run for SMA and everyone of them is exceptional.

And once again we were specifically privileged to have 20+ Greater Toronto Area independent Esso Dealers, along with Imperial Oil, support this event. Their support has been growing year after year under the guidance of Richard Hinton from Hinton’s Esso in Milton, ON and Anthony Simanavicius from Imperial Oil. These gentlemen have no connection to SMA except through the Rebecca Run and we are honored to have them volunteer 100s of hours in support of those who live and have lost to SMA.

Thanks to Volunteer Director Sharon Mountford, and Set Up/Clean Up Director Paul Smith, 100+ volunteers moved through the motions like a well-oiled machine.

“The Rebecca Run continues to grow as a meeting place for families with SMA,” says

Race Director Louise Smith. “The goals of the Rebecca Run have always been: support medical research financially; and offer an event where the people immediately affected with SMA could connect and find comfort and inspiration from each other. Little did we know six years ago that we would also offer the opportunity for friends and extended families to change their feelings of helplessness to feelings of helpfulness just by being involved.”

Join the 7<sup>th</sup> annual Rebecca Run for SMA on July 5<sup>th</sup>, 2008. Registration opens this fall. [www.rebeccarun.com](http://www.rebeccarun.com).



## Today I am Thankful For...

By Christina McDonald

Every day in life, whether we realize it or not we have something to be thankful for.

In May, our eight-year-old daughter Natalie—who has SMA Type II—needed to have surgery. She suffers from scoliosis that had caused her rib cage to meet the top

of her hip and was slowly crushing her insides and causing her pain.

Natalie was so brave, when she was wheeled away from us she didn’t even shed a tear. My husband and I were much more worried—though of course we were awake and watching the minutes tick

by. Thankfully, the doctor was amazing and the surgery was a great success! After they brought Natalie to the PCCU (pediatric critical care unit) and settled her in, we were allowed to see her.

I knew my little girl was going to have all this stuff—but

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Natalie McDonald and her brother Wyatt

## Hippotherapy and CanTRA

The word 'hippotherapy' comes from the Greek 'hippos' meaning horse and 'therapy' meaning care. Thus, hippotherapy is the utilization of the horse for therapeutic purposes rather than equestrian goals.

This new field targets acquisition of motor pre-requisites rather than equestrian abilities. Hippotherapy is a rehabilitation strategy using a mobile and live instrument that just happens to be a horse.

Part of the success in this form of therapy relies upon the fact that the horse possesses motor and emotional neuro-sensitive stimulation qualities that can never be equaled by a machine.

The horse also offers 110 multidimensional movements by impulsion/minutes. No therapist, no matter how motivated or talented, can compete with this quality stimulation.

Hippotherapy is a specialization reserved to rehabilitation

specialists: physiotherapists, occupational therapists, and speech language specialists trained in this field.

In hippotherapy, the rider does not influence the horse but rather the movement of the horse stimulates postural and muscular reactions on the rider. The rider will take different positions on the horse to stimulate effected group muscles.

Objectives are not essentially motor; they can be of all types (cognitive, behavioral, etc.) depending on the initial evaluation prepared by the therapist (OT, PT, speech language specialist) with the help of the rider's medical team.

Founded in 1980, the Canadian Therapeutic Riding Association (CanTRA) is a registered charity that promotes challenge, achievement, and empowerment for children and adults with disabilities through the use of the horse.

There are now approximately 100 member centers

across Canada. Each center offers a program with a slightly different focus. Some offer hippotherapy, others focus on the mental health benefits of riding (Equine Facilitated Mental Health).

The majority of member centers focus on therapeutic riding to provide socialization, recreation, interaction of clients and horses, and the care and training of the horse.

In addition, many of the centers provide life skills training, rehabilitation and employment opportunities for individuals with disabilities.

CanTRA is a member of the Federation of Riding for Disabled International (FRDI) and is recognized by FRDI as the only governing body for therapeutic riding in Canada.

For more information on hippotherapy or to find a member center near you, go to [www.cantra.ca](http://www.cantra.ca).

This article was taken with permission from the CanTRA website. For further information check out [www.fsma.org/hippotherapy.shtml](http://www.fsma.org/hippotherapy.shtml)



Pippa Hodge. The B.C. physiotherapist instrumental in the development of Hippotherapy in the US and Canada at CanTRA 25th Anniversary.

“THE HORSE OFFERS 110 MULTIDIMENSIONAL MOVEMENTS BY IMPULSION/MINUTES. NO THERAPIST...CAN COMPETE WITH THIS QUALITY STIMULATION.”

## What's New with Northern Directions

By Sarah Samplonius, Editor

After five years (time flies) it seemed to be time for a change. Although I've always tried to be environmental—printing on recycled paper and using recycled envelopes—I started to realize the newsletter itself could become a little more

“printer” friendly.

So a revamp was in order to make it more black and white in tone, and simplify the layout, all in an effort to have it use less ink. I hope you find it easy to read as well. Feedback is welcome.

We hope you also enjoy this issue which has some options

for physical activity—more will follow in the next issue with more in-depth stories on specific therapies and their success. Contributions are of course always welcome—we're interested in what you do to keep your kids involved.



Photo taken at SMA Family Camping Trip—Taylor Danielson at one of the many SMA camping challenges.

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**We're on the Web!**  
[www.curesma.ca](http://www.curesma.ca)

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Families of SMA Canada was founded as a Charitable Organization in Summer 2000. Operating as a separate organization from Families of SMA in the States, we work very closely with them, and have access to all their resources. We are a volunteer-driven organization. It is our goal to direct at least 95% of our income to funding research. We represent families in every province.

**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

**TRUSTEES of FSMAC:**

Darren Bray (Manitoba) - [darren@curesma.ca](mailto:darren@curesma.ca)  
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## Thankful, cont'd

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one never can prepare for it. She was hooked up to all sorts of machines and was swollen from all her fluids. We were lucky and my husband was able to spend the first few nights with Natalie in the PCCU.

Every day one or two things were unhooked. Finally we got out of the PCCU and were set up in a regular room—but only for a little while. The next day we were back in the PCCU when Natalie's lung collapsed.

The whole unit jumped in to do what ever they could. My husband and I just stood back while they hooked up some of the items they had only just recently taken off, and added a Bi-Pap machine. They needed to re-inflate her

lung.

We spent two more days in the PCCU before returning to our other room. Our immediate next step was the bathroom—we couldn't even move Natalie without her wanting to throw up. It seemed the anesthetic effect hadn't worn off—she was continuously getting sick.

We all wanted to go home (especially Natalie), but with no fluid intake and no food consumption, and the constant throwing up, we couldn't. Finally on day nine they said we could go home! My husband was packed in minutes!

Three months has passed now. Natalie has recovered well. We're still working on the physio and all the "fun" stuff she loves so much. We

were lucky in so many ways: Our son was able to stay with my mom and stepfather. Even though we live two hours out of town my dad and my stepmother live just three blocks from the hospital. They offered not only a place to stay, but lots of good stuff to eat everyday and an Internet connection so I could keep everyone updated via email.

The email was good for me as an outlet. I tried to leave everyone with a positive note and would end every email with what I was thankful for that day. Through out this event there was a lot to be thankful for. Today I am thankful for the health and love in my home, the nurses and doctors, our friends and family, and—of course—that Natalie is home with us.



Balancing Life's Tough Times™

Northern Directions welcomes submissions. Please send your event, story, or photos via email to the editor, Sarah Samplonius, at [sarah@curesma.ca](mailto:sarah@curesma.ca) or to the main office address of FSMAC