

# WESTERN CANADA FOCUS

ISSUE 1 / SUMMER 2005

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 **Muscular  
Dystrophy Canada**  
*let's make muscles move*

# Director's Welcome

## What is the face of Muscular Dystrophy Canada?

*I think a hero is an ordinary individual who finds strength to persevere and endure in spite of overwhelming obstacles.*

- Christopher Reeve

It is the athlete who inspires us to overcome obstacles; the research scientist whose work transforms equipment design; the Fire Fighter; the business professional; the Harley Davidson owner; the adult client, and the parent, brother or sister of a newly diagnosed child.

Our new edition of *Western Canada Focus* has some unique features to better communicate how the faces of MDC together make muscles move everyday.

First, we've introduced a new feature recognizing administrative volunteers for their dedication to helping make muscles



### WELCOME KEN KRAMER

MDC's western regional office welcomes Kenneth (Ken) Kramer to the position of **Vice-Chair, MDC National Board of Directors**. Mr. Kramer has a neuromuscular disorder, is a practicing lawyer and founder of KMK Law Corporation in downtown Vancouver.

Kramer's other volunteer activities include being a member of the BC Law Society's Equity & Diversity Committee; Director of the Community Legal Services Society; member of the Planned Giving Committee for the Canadian National Institute for the Blind, and member of the Canadian Paraplegic Association.

We are so fortunate to have Mr. Kramer on our team and look forward to his support in the coming year.



move. In the Vancouver office, MDC has utilized over 500 volunteer hours in the last four months. We encourage other regional offices to recognize volunteers who have joined our battle against neuromuscular disorders.

Our new *Spotlight on Research* profiles the outstanding academic talent working to improve outcomes for neuromuscular disorders. We hope you enjoy our article on researcher Dr. Bonnie Sawatzky and her poster on wheelchair maintenance - a pullout section in this issue.

Also new is a feature called *Champions of the Muscle Movement*, profiling an inspirational individual who is advancing the cause. On page 15 you will meet Danielle Peers, Paralympic Bronze Medallist and first woman ever to be selected to the National Wheelchair Basketball Association's (NWBA) All-Star Team.

Finally, this issue would not be complete without recognizing how our staff and communities have worked together over the past year. We continue to challenge ourselves, to move forward, to provide better services and be the best partners we can be.

Thank you all!



Christine McDermott  
Executive Director, MDC Western Canada



## Research Goes on the Road

Chapter President Lori Trepanier and MDC volunteers in Grande Prairie, Alberta, recently invited a group of distinguished researchers to talk about latest discoveries and issues in neuromuscular research.

Trepanier's co-organizer was Tyrel Lawrence, who has Duchenne muscular dystrophy. Lawrence is a graduate of Grande Prairie Regional College with a diploma in Computer Systems Technology. A local youth, Kurtis McNally, was invited to emcee the event and introduce two of the guest speakers. McNally is a 15-year old high school student who has a rare neuromuscular disorder and is a bright young advocate for research and education.

The Conference was aptly titled *Footsteps to the Future* and was inspired by volunteers with a passion for promoting understanding of neuromuscular disorders in their community.


*For information on how to bring research education to your community, call Jennifer Scrubb at MDC's Western Regional Office.*




# Education & Services


## News You Can Use

 The Canadian Disabled Individuals Association (CDIA) web site hosts the *Accessible Housing Registry*. At this time, listings can be posted for the Province of BC and the site includes the BC Paraplegic Association's (BCPA) accessible housing list. Visit [www.disabledindividuals.ca/housing.asp](http://www.disabledindividuals.ca/housing.asp), or for more information call Louise at the BCPA, 604.324.3611 local 211.

 Gas prices leaving you feeling empty? ESSO, Shell Canada, Chevron and Petro Canada all offer full-serve at self-serve prices for

anyone displaying their handicap parking placard. When a station attendant sees the placard in the window of your vehicle, he/she will fill your tank using the self serve pumps, saving you a few cents per litre. Both Shell Canada and Petro Canada offer more information on their websites at [www.shell.ca](http://www.shell.ca) and [www.petro-canada.ca](http://www.petro-canada.ca).

 Need expert legal advice but cannot afford a lawyer? *Access Justice* might be your answer. This free service has the support of more than 400 volunteer lawyers at clinic locations throughout Western Canada. For more information and clinic locations nearest you, visit [www.accessjustice.ca](http://www.accessjustice.ca).

 The BC Community Living Restructuring Fund has just been awarded \$4 million in additional funding from the BC Provincial Government. The CLRF has helped many MDC clients obtain money for extremely costly items including renovations, vans, vehicle modifications and modular homes. This funding will go fast, so MDC encourages you to submit applications. For more information, go to the CLRF website at [www.clrestructuringfund.ca](http://www.clrestructuringfund.ca).

## QUICK FACTS

- MDC British Columbia registered 39 new clients in 2004/05. There are currently 1,168 people with neuromuscular disorders registered in BC.
- Alberta registered 23 new clients in 2004. Alberta now serves 1018 clients with neuromuscular disorders.
- Manitoba saw eight new registrants last year, for a total of 363 clients.
- Saskatchewan registered eight newcomers and now serves 320 clients.



## YOUTH MATTERS

"My name is Lauren Wadsworth. I am 19 years old and was diagnosed at age 8 with the neuromuscular disease called Myasthenia Gravis.

Myasthenia Gravis causes muscle weakness in all my muscles and it affects my walking, chewing, swallowing, breathing, eyesight, talking, coordination, and physical stamina. It also makes me consistently weaker and less able to do for myself as time has gone on.

It has been a struggle everyday just for me to live a decent quality of life and there is no guarantee that I will live a full life, although I never give up hope. I recently wrote a book about my life and struggle with Myasthenia Gravis. It is titled *Giraffe Girl* and it was published by *Publish America*. It's official release date is August 22nd 2005 but it is available now to order at [www.publishamerica.com](http://www.publishamerica.com). In the coming weeks it will also be available through [amazon.com](http://amazon.com) and [barnesandnoble.com](http://barnesandnoble.com) I was hoping you could do an article in your newspaper about my book and my story."

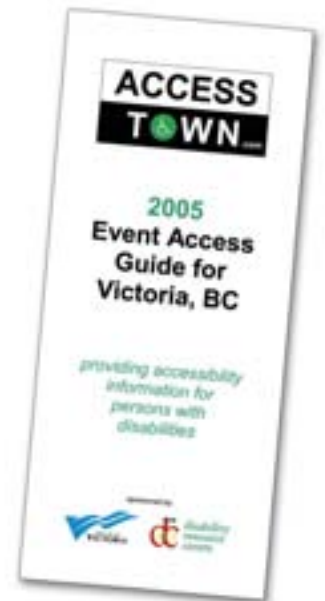
*Received from Lauren Wadsworth from Surrey, BC, by email, June 27th, 2005. Giraffe girl is the story of a young girl's journey through life with chronic Myasthenia Gravis. It showcases the hardships and triumphs she endured with this devastating disease and the turmoil it brought upon her family. Giraffe Girl is a unique, realistic, honest experience that reflects the normality of a young girl, despite her physical problems.*

## Melchior Does it Again!

Luke Melchior, entrepreneur, documentary film star (if you haven't seen *Bearing Witness*, do so right now) and nominee for MDC National Ambassador, has developed an event guide for people with mobility challenges. Based in the City of Victoria, the guide uses a colored key to illustrate access points, washroom facilities, costs and parking for some of the city's premier events. Plans are in the works to adapt this unique idea to other Western Canadian cities.

To view the complete guide, visit Luke Melchior's *AccessTown* website at [www.accesstown.com](http://www.accesstown.com).

Looking for outdoor adventure gear? Check out Mr. Melchior's online store *Modern Outpost* at [www.modernoutpost.com](http://www.modernoutpost.com). Partial proceeds from all sales are donated to MDC.



## Building Bridges

### ***Bridges to the Future Expands to Alberta***

It has been nearly two years since we introduced *Bridges to the Future*. Since then, the program has grown to serve almost 100 youth, with support from the BC Paraplegic Association and Spina Bifida and Hydrocephalus Association of BC. Under the guidance of Provincial Coordinator, Paula Faragher, *Bridges* is rapidly gaining a reputation as the premier program for networking, peer support, life skills and employment training for youth with physical disabilities.

In April, Kristie Coulombe in Edmonton assumed her new role as *Bridges* Coordinator for Alberta. "Our goal is to have 30 youth involved in the Alberta program this year, and to double our



*Say cheese! Youth ham it up at a BC Bridges social event*

participation by the end of 2006," says Coulombe.

Funding for *Bridges* Alberta was made possible by the Wild Rose Foundation, Stollery Charitable Foundation, and Allard Foundation.

Progress is now underway to expand *Bridges* to Saskatchewan, as part of our ultimate goal to offer this program to all Canadian youth with physical disabilities.

*"Keep your fears to yourself, but share your courage with others."*

– Robert Louis Stevenson



# Meet OUR Volunteers

## Getting to know you...

In January, MDC's Vancouver office, under the guidance of Dawn Smith, embarked on a volunteer recruitment program.

This section is the first in a regular feature on volunteers. Here you will meet five volunteers — Nancy, George, Brandon, Sviatlana and Lucian – who have put in hundreds of hours to help make our jobs easier.



**Nancy Backer**

**Hometown?** Vancouver, BC.

**Nickname?** Backwards, or Nandy

**Why do you volunteer for MDC?** Because I enjoy the environment.

**What are you most proud of?** I'm most proud of the award I got in March, 2005, for seven years of volunteering at BC Disability Sports.

**What was your favorite subject at school?** Spelling. Whenever I had a spelling test I would not need to study for it and would get all the words right. Ask me to proofread.



**George Brinton**

**Hometown?** Paradise, Nova Scotia.

**Why do you volunteer?** Because I have muscular dystrophy and want to be part of the team that finds a cure.

**Likes?** Hockey, bingo and baseball.

**Dislikes?** Rude people.

**Favourite quote?** Do unto others as you would have them do unto you.

**What achievement are you most proud of?** Being here with all of you beautiful people. (*Aaaw, shucks*).



**Brandon Law**

**Why do you volunteer?** I need something to do in my spare time.

**What has volunteering done for you?** It has given me the opportunity to apply my skills to help. I am more aware of the various neuromuscular disorders that have a huge impact on people's lives. And I don't procrastinate as much.

**What is your greatest achievement?** Nothing ground-breaking. I once built a Passlabs Aleph 3 stereo amplifier from scratch, using only the schematics provided in the service manual. (*Say what?*)



**Lucian Dinu**

**Hometown?** Mangalia, Romania.

**Why do you volunteer?** I have a neuromuscular disease (CMT) and my children will probably get it too. I want to contribute to the efforts of those trying to find a cure.

**What was your favourite subject in school?** Math.

**Most admirable trait in others?** Sincerity.

**What do you do when you're not at MDC?** I'm a Software Consultant.



**Sviatlana Maslenikava**

(pictured left, with volunteer coordinator Dawn Smith)

**Hometown?** Minsk, Belarus.

**Why do you volunteer?** I want to understand more about Canadian life and work habits, and to help people.

**What has volunteering done for you?** It has helped me make new friends and gain job experience.

**What achievement are you most proud of?** My family.

*Have a volunteer that you want to recognize? Contact Dawn Smith at dawn.smith@muscle.ca And ask for a 'Meet Our Volunteers' questionnaire. Forward the answers to Anne Williams at anne.williams@muscle.ca.*



# Muscle for Muscle

## New Partners

### Shamrocks & Lilydale Towel Power

**MDC is pleased to welcome the Victoria Shamrocks and Lilydale to its team roster.**



The Victoria Shamrocks Senior Men's Lacrosse team - Canada's 2003 Mann Cup Champions - has launched 'towel power' to raise funds for MDC. For the first time in Canadian lacrosse history, fans waving the 'rally towel' will be helping the Shamrocks in their fight against neuromuscular disorders.



One hundred percent of proceeds from each \$2 towel sold will benefit MDC, thanks to corporate sponsor, Lilydale Foods. Lilydale has its roots in Alberta and got its start feeding troops overseas during WWII. The company is now one of Canada's largest fresh food suppliers.

For more information visit [www.victoriashamrocks.ca](http://www.victoriashamrocks.ca)



### BCHRMA Chooses Bridges as Golf Charity

The BC Human Resources Management Association (BCHRMA) has chosen *Bridges to the Future* as charitable recipient of its annual golf tournament. Bridges Coordinator Paula Faragher and her assistant, Kate Petrusa, are working with organizers to include youth in the fun event, where they will get to meet some of BC's top Human Resources professionals. MDC hopes to partner with BCHRMA to make this tournament an annual tradition.



### ESAA Swings Into Action

The Environmental Services Association of Alberta (ESAA) held its 10th Annual Golf Tournament on July

### Lucky Charms The Running Room's Elf Run



*The Running Room presents a cheque from the 1st Annual Elf Run to MDC Calgary Chapter President, Rachelle Shipley*

15th at the Alberta Springs Golf Course, just north of Red Deer. Each year, the ESAA gives all proceeds from mulligan sales and its silent auction to MDC. Funds are designated to spinal muscular research in memory of Ilsa Mae Chowaniec, who passed away from Spinal Muscular Atrophy on March 28th, 2000, only a few short months before her second birthday.

### Massage Therapists Flex Their Muscles



Need a massage? This August through October, more than 100 members of the Massage Therapists Association of BC (MTABC) will donate proceeds from the sale of massage certificates to MDC. The public can buy these certificates anywhere that a participating MTABC member operates.

Certificates are only \$35 each, with \$20 going to fight neuromuscular disorders. This unique fundraiser is sure to be a huge hit and will sell out fast, so stay tuned for more information and a media campaign coming in July.



Dr. Bonita Sawatzky (Bonnie) is a researcher at Children's Hospital in Vancouver in the Department of Orthopaedics, and has a PhD in biomechanics from Simon Fraser University. Dr. Sawatzky's work is focused on ways to improve mobility in children with disabilities.

Just prior to beginning her PhD, Dr. Sawatzky was involved in a car accident and now uses a manual wheelchair as her primary mode of transportation. Her interest in wheelchair research was sparked by curiosity about the variety of options available to wheelchair users, such as suspensions, tire types, wheels and cushions, and how they affect one's energy.

One of Dr. Sawatzky's studies helped to determine the effect of tire inflation on energy expenditure. Energy expenditure was measured in 34 adult spinal cord injury (SCI) subjects with tires inflated to different pressures. Results showed that tires must deflate 50% before they affected energy expenditure significantly.

Dr. Sawatzky's team also looked into how inflatable tires affected rolling resistance compared to solid tires. Interestingly, solid tires performed worse than inflatable tires at 25% of their recommended tire pressures. This means that if an individual chose solid tires for everyday use, they would be working up to 50% harder to propel themselves forward than if they used inflatable tires.

Dr. Sawatzky's tire study won the Founder's Medal awarded by the 2003 Canadian Orthopaedics Research Society.

Tires have shown to play a critical role in wheelchair mobility; however, wheels themselves are also part of the equation. A relatively new wheel on the market, the Spinerger wheel, is promoted as being better and lighter. Dr. Sawatzky and her

# Spotlight ON Research

## Dr. Bonnie Sawatzky

colleagues at GF Strong Rehabilitation Centre investigated these claims by examining energy expenditure and comfort using Spinerger wheels.

The teams found no improvement in energy expenditure with Spinerger wheels; however, participants preferred them. "These wheels may have an element of vibration-dampening that plays a role in personal preference," explains Dr. Sawatzky. "We are currently studying the effects of Spinerger wheels on vibration and spasticity. If the team can show that the wheels may decrease these problems during wheeling, some people may be able to use less medication to deal with their spasticity."

Children do not seem to get wheelchairs that are as functional as adults'. Another of Dr. Sawatzky's studies will look at adults and children who use power and manual wheelchairs and ask questions about their satisfaction. The hope in all of this research is to gain a better understanding of how clinicians can minimize long-term overuse problem associated with wheelchairs.

*Bonnie Sawatzky and her team often need participants to help with their research studies. To find out more, contact Dr. Sawatzky at 604-875-2345, local 7274, or by email at [bsawatzky@cw.bc.ca](mailto:bsawatzky@cw.bc.ca)*

### QUICK FACTS

The City of Vancouver is the only city in North America to elect a person with a significant disability to City Council. An even greater achievement is that citizens of Vancouver have elected two! – Councilors Sam Sullivan and Tim Louis. Both have quadriplegia and wield significant power at City Hall.



# Zen and the Art of Wheelchair

Poster by Dr. Bo

## Push Handles

- secure and tighten bolts to ensure safety



## Upholstery

- clean regularly with soap and water to decrease risk of skin breakdown and infection
- clean spills as soon as possible



## Brakes

- check that brakes are secure and all nuts and bolts are tight
- apply WD40 to the movable parts of the brake lever monthly



## Castors

- clean and lubricate castors with WD40 every month
- dirt and debris wear out wheels faster
- make sure castor is 90° to the floor to minimize fluttering



## Footplate

- ensure nuts and bolts are tight to prevent unwanted footplate movement

See your wheelchair dealer once a year for an

# Wheelchair Maintenance

Donnie Sawatzky

## Axles

- ▶ lubricate with WD40 every 3-4 months to improve wheel function



## Spokes

- ▶ tighten spokes every 6 months to ensure wheels stay round and true
- ▶ repair broken spokes immediately



## Push Rims

- ▶ check push rims and remove sharp burrs with fine sandpaper to prevent scrapes and blisters

## Tires

- ▶ ensure tires are inflated to the recommended pressure written on the sidewall of each tire
- ▶ pump tires every 2 weeks
- ▶ flat tires make wheeling much harder and affect brake function
- ▶ check tread wear regularly and replace if worn



ate  
s are tight to avoid  
ovement

an annual tune-up and complete inspection

# Fire Fighter News

## A Message From Lorne West

**Vice President, 6th District, International Association of Fire Fighters.**



It is with great pleasure that I welcome Donna Dowsett to the role of National Manager, Fire Fighter Development, and

Anne Williams to the position of Corporate & Media Relations Development Coordinator for Muscular Dystrophy Canada.

As fire fighter relations lead for Western Canada for the past few years, Ms. Dowsett has been a committed advocate for fire fighters and the recognition of their contributions to MDC. As District Coordinator, in 2004 she spearheaded the '50 Boot Drives in 50 Days' campaign to recognize the 50th anniversary of fire fighters' fight against neuromuscular disorders.

Since joining MDC in January, Ms. Williams has already helped a number of fire departments in Western Canada achieve public recognition for their charitable work. Ms. Williams has a lengthy background in social marketing, which includes several years in media relations for BC Children's Hospital.

The IAFF and MDC have the longest-running partnership in

Canada between a public service organization and a national charity. MDC recognizes the tremendous contributions of IAFF members and this year has set out to achieve greater awareness of this historical partnership among the Canadian public.

We look forward to some exciting new initiatives across the country as fire fighters, MDC staff and volunteers continue to strengthen the bond that will one day bring a cure for neuromuscular disorders.

## Men & Women With Brooms

### **Fire Fighters Curling Championships second only to Brier**

"An emotional roller coaster" were the words used to describe the 46th Annual Canadian Fire Fighters Curling Championships (CFFCC) held in Yellowknife from March 23 to April 3, 2005.

The CFFCC is the only competition that gathers fire fighters from every province and territory in Canada to compete for a national championship, and is second only in size to the legendary 'Brier Cup'.

Having just experienced the tragic loss of two of their own – Kevin Olson and Lt. Cyril Fyfe from Northwest Territories Local 2890 – Yellowknife decided to carry on with the event as a way to help heal from their loss.

The 46th Annual CFFCC became more than a competition – it was a place to honor, reflect and appreciate the strength of the fire fighting community.

Spectators at this year's Championships witnessed a Western Canadian sweep, with Alberta, Manitoba and BC taking first, second and third place respectively.



*Team Manitoba (L to R): Lead: Rick Mullin, Second: Bev Stewart, Third: Byron Zbirun, Skip: Rick Kinaschuk, Director: S.R. Bob Poole.*



*Team Alberta (L to R): Director: Brian Godfrey, Lead: Brian Hoekstra, Second: Gary Hoekstra, Third: Livio De Prato, Skip: Jim Henderson.*



*Team BC (L to R): Lead: Tom DeSorcy, Second: Al Trick, BCFFCA Sec. Treas.: George Hallinan, Third: Glenn Wejr, Skip: Don Druet.*



Muscular Dystrophy Canada received donations through a variety of fundraising events including raffles, a silent auction and an impromptu head-shaving (a lesson in keeping a low profile in the host lounge!)

MDC thanks the CFFCA, President Lyle Wiebe and Northern Ontario Director, Ken Kurz, for inviting MDC to be part of this inspiring and prestigious curling event.

*The 2006 Championships will be held in Ottawa, Ontario. For a list of Provincial playdowns or information on how you can get involved in the CFFCA, visit [www.cffca.ca](http://www.cffca.ca)*

## CANADA'S FIRE DEPARTMENT OF THE YEAR

Fort McMurray has been named 2004-05 Fire Department of the Year by MDC representatives from across Canada. With events including a boot drive, charity hockey game, sports memorabilia auction and a pancake breakfast, MDC Chair Steve Kozelenko and Fort McMurray Fire Fighters raised more than \$42,000 for MDC last year – more than any other department in Alberta and the Northwest Territories.



*(L to R) Fire Fighters Mike Sullivan and Troy Palmer proudly display their #1 banner at recent Pancake Breakfast fundraiser.*

## Grande Prairie 'Aces' Buck for Luck

**Say it fast three times.....**

Egan McSwiggins is not only a tongue twister, in 2005 it was among the top two pubs in the nation in fundraising for MDC's Buck for Luck campaign. On March 10th, the Irish-themed pub in Grande Prairie, Alberta, held a charity poker tournament where players collected pledges to buy betting chips. The best player claimed bragging rights while MDC came out the ultimate winner with more than \$4,000 in donations. In total, Egan McSwiggins raised \$5,770 during the campaign.

First place in the country went to the Lion's Den Pub, also in Grande Prairie, whose patrons raised a staggering \$9,000 for MDC in one night. The Lion's Den held a 'Potato Bob', where patrons sponsored each other to bob for floating potatoes. The lucky bobbers could also buy their way out of the competition (a popular choice).

For it's part in coordinating the festivities, Grande Prairie was aptly named the country's #1 Buck for Luck Fire Department, raising a whopping \$19,505.03.

*Want to organize a hold 'em poker fundraiser? Call Jo-ann Burton in Edmonton for contact information.*



## Fielder's Choice

**Cowichan Valley fire fighters hit home run for MDC**

When Fire Chief Nick Soyhe coordinated the first Mesachie Lake Fire Fighters Ball Tournament in 1979, he never realized how much it would come to mean to his family and community.

The first Mesachie Lake tournament raised \$150 — enough to build an addition to the local fire hall. The event was so popular that the organizers decided to make it an annual fundraiser and MDC its official charity.

Two years later, Nick and his wife Sherry found out that their son Adam had muscular dystrophy. At nearly the same time, Nick's colleague Doug (Deputy Chief of the Duncan Fire Department) and his wife Debbie learned that their son Grady also had the disorder.

"When we found out about Adam and Grady, participating halls immediately adopted the boys as





(L to R) Fire Fighters Russ Ricketts and Rob Heppell of the Saanich Fire Department

## BOOT DRIVE

### News from across Western Canada...

#### The rubber hits the road...

The first Western Regional Boot Drive is less than two months away. On September 23rd and 24th, Fire Departments from BC to Northern Ontario will come together to raise funds and awareness for their historic support of MDC.

Spring Boot Drives have already given us a hint of what is to come. **Atikokan** and **Sioux Lookout Fire Departments** in Northwestern Ontario and more than a dozen departments on Lower Vancouver Island all held boot drives on May 27th & 28th. Atikokan raised just over \$4,000, while together the **Fire Departments of Lower Vancouver Island** broke a previous record – raising \$64,211.00 in two days.

A post-Boot Drive report and pictorial will appear in the next issue of Western Canada Focus.

*There is still time to get in on the regional publicity and promotional opportunities for the September boot drive across Western Canada! To sign up, please call Donna Dowsett at our regional office.*

their own and the tournament took on a whole new meaning," recalls Sherry.

Having just completed its 26th year, the Mesachie Lake tournament is approaching the half-million dollar mark in fundraising for MDC. This year's tournament, held June 17 –19, raised more than \$30,000 and attracted 78 players representing eight fire departments: Mesachie Lake, Youbou, Lake Cowichan, Honeymoon Bay, Caycuse, Duncan, Cowichan Bay and Langford.

*For more information on the tournament, call Sherry Soyhe at 250-749-6914.*

## Do you Believe in Magic...?

**Calgary Fire Fighters** brought *Magic and Miracles* to their city in January to help fight neuromuscular disorders. The event delighted families with magic and illusions from some of North America's best stage performers. Following the event, the Calgary Fire Department presented MDC with a donation of \$25,000.

## Footloose...

Twenty-five children from the northern community of Leaf Rapids, Manitoba, held a Dance-A-Thon for MDC, raising an impressive \$882. The dance ran from 6p.m. to 12a.m. and included a free BBQ supper supplied by the local Fire Department and United Steelworkers Local 1844. All tolled, the event raised \$1,100. Way to go kids!

## FIREFIT COMBAT CHALLENGE

The *FireFit Combat Challenge* makes its way across Canada this year, and MDC will be there to show its support. Two upcoming events are in Western Canada – the Strathcona, Alberta Combat Challenge on September 10th and the National Championships in Edmonton from September 15th – 18th. Get out there and cheer for your local crews! For more information visit [www.firefit.com](http://www.firefit.com)

## A New Kind of Skins Game



*Fire Fighters Brian and Gary Hoekstra of Edmonton and Pat Rowe of Fort Simpson couldn't escape the razor*

*at the Fire Fighter Curling Championships. Actually, quick-thinking Brian (left) shaved his own head prior to the event. He then volunteered to shave the head of his brother, Gary. Pat put up the \$1000 bid to shave Gary's head, after which the Northwest Territories pulled a fast one on Pat. Nice mohawk Pat!*



*Saskatchewan Fire Fighters raised \$2,742 in a bidding war to see outgoing Executive Director of the Saskatchewan Association of Fire Chiefs, Don Zolmer, lose his hair. Doing the shaving is incoming ED, Peggy Antonichuk, and Kamsack Fire Chief, James Pollock.*



# The Harley Scene

## A Sound Investment

The Spring issue of Canada's *Investors Group Review* magazine features the amazing contributions of IG consultant David Page.

In 1976, Page bought his first motorcycle – a 125 Honda XL. Gradually he worked his way up to a Harley Davidson. A few years ago, Page attended a Harley Owners Group (HOG) Chapter meeting to find out how he could combine his love for riding with local charity work. It wasn't long before Page was elected HOG Chapter President.

Last year, Page and his dedicated team of volunteers raised more than \$19,000 for MDC during the Kamloops *Poker Run* – an annual 300 km ride and Harley Raffle that donates 100% of its proceeds to fight neuromuscular disorders.



David Page (far right) and his HOG Chapter volunteers present a cheque for more than \$19,000 to MDC Kamloops Chapter President, Carolyn Lefferson (photo courtesy of Investors Group)

Over the past 16 years, Kamloops HOG has raised a whopping \$600,000 for MDC.

Carolyn Lefferson, MDC Chapter President, expresses her thanks in the national IG magazine article. "Words can't explain how I, as a mother of a son with muscular dystrophy, feel when I see all of these people gathered together for one important cause (and some great fun too...of course)."



Smithers Fire Fighters stand with Harley Davidson winner.

## Wheels on Fire

BC's Northern Interior Chapter is an example of what can happen when MDC's two top fundraising partners — HOG and Fire Fighters — come together for one great cause. Fire Fighter Kelly Zacharias and the Smithers Fire Department raffled off a Harley Davidson in March — raising a record \$27,000. The winner turned out to be none other than a local fire fighter!



*MDC client, Walt, and his dog Beau*

*"Some thoughts on this transitional time in my life, graduating to a wheelchair from painful walking with a cane and two leg braces. Very excited... I can move around faster and quicker than I could when I was well. And no pain, I can now stop and talk to a friend for some time without looking constantly for a 'landing spot' for my butt. Something about smelling the roses, finally. What fun, and my cane is in the truck where it belongs."*

*- email received from Walt, an MDC Client, upon receiving a wheelchair through the equipment loan program, March 2005.*

## Ryan's Run

In Northwestern Ontario, Neebing and Oliver Paipoonge Fire Departments helped Angelo Paternoster and his volunteers pull off another hugely successful Ryan's Run, a motorcycle 'poker run' in memory of Angelo's son who passed away from a severe form of Spinal Muscular Atrophy at only ten months of age.



*Angelo Paternoster and his wife (front row, wearing white), their team of dedicated volunteers and riders at this year's Ryan's Run, held May 28th, 2005 in Thunder Bay, Ontario. Paternoster is Co-President of the North of Superior MDC Chapter along with Fire Fighter Advisor Steve Davey of Neebing Fire Department, whose daughter has a neuromuscular disorder.*

## AND VOLUNTEER OF THE YEAR GOES TO:

Susan Andrist, client and President of BC's Northern Interior Chapter, has been awarded National Volunteer of the Year by MDC. Ms. Andrist inspired local volunteers to develop the 2004 Muscle Run in honour of MDC's 50th Anniversary. The inaugural event attracted more than 100 riders, stopped in seven northern interior communities and raised approximately \$10,000. Ms. Andrist made sure that clients and volunteers were at each stop to personally thank the riders for their support. Way to go, Susan!



# Setting the Gold Standard

## **Paralympian Danielle Peers**

Despite suffering progressive leg pain from the age of seven, Danielle Peers excelled at her favourite game – basketball – through her childhood and teen years, achieving the status of All-City, Provincial All-Star and finally Academic All-Canadian by the age of 20.

In her second year of college, Peers' leg pain became too much to handle. Told by doctors that her pain would subside if she gave up basketball, Danielle decided to put away her court shoes and try coaching. As coach, she led Grant MacEwan College to a #1 National ranking in 1999-2000.

It was around that time when a spectator suggested that Danielle try out for the wheelchair basketball team. Peers remembers, "It took 13 minutes for me to fall in love with wheelchair basketball. It has the strategy of sailing, the speed of bike racing, the aggression of hockey and the finesse and athleticism of basketball."

It was not until a routine classification at a game three years later that a physiotherapist suspected Peers' pain was due to more than just years of playing hard.

Taking the physiotherapist's advice, Peers visited a neurologist who diagnosed her with Limb-Girdle, a



# Champions OF THE Muscle Movement

form of muscular dystrophy that affects mostly the legs and shoulders. Says Peers, "After my diagnosis I decided that I had a choice between sitting at home and getting weaker every day or going out and chasing a dream, and getting stronger where I could despite my weakening legs."

Peers began an intense, 30-hours per week training regimen. "In six months I made the Canadian National Wheelchair Basketball Team, and a year later I was heading to Athens for the Paralympics."

Peers' team returned from Athens with the Bronze Medal. Then in 2005, Peers and her Alberta Northern Lights squad became the first Canadians in 57 years to win the 2005 National Wheelchair Basketball Association (NWBA) championships. Peers also achieved an historic milestone, becoming the first woman in history to be named to the previously all-male NWBA All-Star Team.

Peers plays down her achievements. "People think the Paralympics is about overcoming obstacles. It's not. It's no different than any other

endeavor for any other person. It's about seeking out obstacles, chasing them, tackling them, and getting tackled by them. It's that process that keeps us alive and strong."

When she isn't on the road or training for her next triumph, Peers takes time to volunteer for MDC as a motivational speaker to support people with neuromuscular disorders. Peers helped launch the *Alberta Bridges to the Future* program by donating her time to speak to youth attending the launch event. As well, Peers was a keynote speaker at the *Footsteps to the Future* conference in Grande Prairie in June.

Peers' attitude can best be described by these words on her website: "I spent over 3,000 hours training for Athens, I spent three minutes on the podium. It's not the podium that made it worthwhile. I had won before I even played."

*For more on Danielle Peers, her contributions to sport and MDC, visit her website at <http://www3.telus.net/public/tunz>*



# WESTERN CANADA FOCUS

## We Need Your Help

### Funding For Essential Equipment

One of MDC's biggest challenges is the ever-rising cost of equipment, much of which is not covered by government services. For example, a motorized wheelchair can cost as much as \$35,000 – the same price as a mid-sized SUV.

Chapters, Fire Fighters, Harley Owners and corporate partners are crucial in our efforts to meet the needs of clients who come to MDC as a last resort when all other sources of equipment have been exhausted.

### MDC Equipment Program expenditures by province, fiscal year 2004/05

BC: \$365,272

Alberta: \$174,328

Saskatchewan: \$17,007

Manitoba: \$28,675

**To make a donation,  
please call 1-800-366-8166**

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## WANT TO BE AN MDC VOLUNTEER?

Call or email your nearest Chapter to find out how YOU can help in the fight against neuromuscular disorders!

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