



Canadian
Paraplegic
Association
(Manitoba) Inc.

Association
canadienne des
paraplégiques

MPF MANITOBA
PARAPLEGIA
FOUNDATION INC.

March 2003

Spring Edition

PARATRACKS

Newsletter of the Canadian Paraplegic Association (Manitoba) Inc.



Orpha and Arnie Schryvers: Through the Years

In this issue....

Orpha and Arnie Schryvers bid Adieu
Incomplete Injuries and the People With Them
FES: Zapping Your Way to Good Health

Plus People Profiles Proliferating Plenty of Pages



ParaTracks is a publication of:

Canadian Paraplegic Association (Manitoba) Inc.
825 Sherbrook Street
Winnipeg, Manitoba R3A 1M5

Tel: (204) 786-4753

Fax: (204) 786-1140

Toll-free: (800) 720-4933 (within Manitoba only)

E-mail: winnipeg@canparaplegic.org

Website: www.cpamanitoba.ca

Supported by Manitoba Paraplegia Foundation Inc.

Circulation: 1,100 copies
Estimated Readership: 5,000

Editor: Ken Davis

Layout: James Kraynyk

Advertising Rates:

Effective January 1, 2001,
advertising rates for photo ready copy:

Full Page - \$160

Half Page (Back Cover) - \$100

Half Page - \$87

Quarter Page - \$55

Business Card Size - \$33

Classified ads free to CPA members.

*Paratracks publishes
three times a year*

Canada Post Publication Agreement #40050723

Board of Directors

- *Randy Komishon - President
- John Thorpe - Vice-President
- *George Dyck - Past President
- *Leonard Steingarten - Treasurer
- *Norma Amadeo
- *Regan Block
- *Art Braid
- *Lorne Chartrand
- *Corrine Deegan
- Dr. Karen Ethans
- Ed Giesbrecht
- Ernie Hasiuk
- Marlene Hanson
- Rudy Niebuhr
- *Lou Ella Shannacappo
- Kay Stewart
- *Roger Traverse

**paraplegic or tetraplegic*



Gone But Not Forgotten

It was with deep sadness that we announced the sudden passing of CPA's long-time Accountant, David Lewicki on March 11, 2003. Dave is missed dearly by CPA staff, and by many Board members and clients who knew him.

Dave received his Bachelor of Commerce Degree from the University of Manitoba and became a Chartered Accountant. Prior to joining CPA in August 1994, he worked as a Senior Manager at Deloitte & Touche. He was very dedicated,

reliable, and competent, and his work ethic was second to none. In many ways, he was known as the "father figure" among CPA staff – he made great coffee (he didn't think we could do as good a job at this) and we miss his practical jokes and 'frank' sense of humour. Dave was also a very generous person who cared about others' well-being. Rest in peace, our friend....the office just isn't the same without you.

Welcome Roslyn Dooley

CPA would like to welcome Roslyn Dooley. Roslyn will be replacing Dave as the new accountant. She can be reached at 786-4753 ext.221 or by e-mail at rdooley@canparaplegic.org

Letters to the editor can be mailed to:

Ken Davis

755 Buckingham Road

Winnipeg MB R3R 1C3

or emailed to Ken at spinaldamage@shaw.ca

Saturday, May 3, 2003 Symposium

(See Brochure Insert)

“Live Your Present, Build Your Future”

For people living with spinal cord injury and brain injury

Club Regent Casino Hotel

1415 Regent Avenue West, Winnipeg

Registration \$25.00 per person - April 18th deadline

(registration fees may be waived in exceptional circumstances, please call CPA for details)

Limited transportation subsidy will be available on a first-come, first-serve basis. Please call Adrienne Conley at 786-4753, ext. 222 to arrange for transportation.



A Farewell Interview With Orpha and Arnie Schryvers

by Scott Byiers

Arnie Schryvers has been a fixture on the Spinal Cord Injury ward of the Rehabilitation Hospital as CPA's Hospital Rehabilitation Counsellor for 28 years. Both he and his wife Orpha, who has been a nurse at the hospital for 31 years, are known, respected and even loved by hundreds of people, including hospital staff and ex-patients of the SCI unit. Arnie and Orpha have made many friends in many places as a result of their caring, courage and commitment to the rehabilitation of persons with spinal cord injuries. Their joint retirement in December 2002 leaves a definite gap at the Rehabilitation Hospital and at CPA, which is unlikely ever to be filled.

Before heading off to their retirement cottage near Kenora, Arnie and Orpha graciously shared with me their recollections of their years at the hospital, as well as their candid assessment of the state of the current medical system with regard to persons with SCI.

When did you start working at the Rehabilitation Hospital?

O - April 10, 1972. **A** - February 3, 1975.

What do you remember most from that period of time?

A - The thing that I was impressed with about the spinal cord program, was that there was a program, which included the client. We had a team effort, we had team conferences, and we had a follow-up program and it all seemed to flow naturally from the time a person was admitted to the time a person was discharged. Over the last eight years, due to changes in health care delivery and whatever, that has changed a lot.

Orpha, how about you?

O - I think I also look at the changes that have occurred at the spinal cord injury unit over the years. When I first started working on the ward as a nurse, the whole ward was just kind of like a rehab ward and there wasn't a special spinal cord injury program. The admissions were long - we got to know patients very well because they were in the hospital for long periods, and they would come back every year for their kidney checkups. Today, you just don't see that kind of thing. You got to know the patients so well because you saw them year after year.

Then Dr. Dubo and I developed the outpatient program because patients didn't have any place to go after they left the hospital. They didn't know who to go to when they ran into problems - their family doctors didn't know how to treat the

problems they were running into and there was no outpatient department here for them to go to, and so they would come back to the ward. I was the one who had been here the longest, so they recognized me, and they would come to me. I was spending half of my time with outpatients and that is how the outpatient program got started.

I left the ward the same weekend that we got married. I was on the ward and we hadn't told anybody that we were going together. People would see us together but they didn't realize that we were going together. When we got married it all coincided; it all just worked out beautifully. This position got started so I could leave the ward.

The outpatient program got started doing kidney checkups, and then following people once they were discharged from the hospital. That is when they were trying to get into their bladder and bowel routines, preventing pressure ulcers, and learning all of that. In the hospital, it's fairly simple but once they go home, it's a lot more challenging, especially with the bowel routine. Also, I was like an emergency department or an urgency department. When people did run into problems with urinary tract infections, they could come and get treated right away. That's something that's missing today.

I was just talking to someone who was trying to get into see a doctor at a clinic, but he phoned three clinics and was told "we're not doing walk-ins."

O - Family doctors are not easily accessible, and people with spinal cord injury, when they run into problems with urinary tract infections, get sick very fast and need attention very fast. So at that time, I was keeping track of everybody's urine cultures regularly and so it was easy when somebody came in with symptoms. I knew what they tended to grow and knew what treatments worked. Then of course, there was the prevention of pressure ulcers. I know it's hard to get people treated for pressure ulcers or get them into the hospital when they need it. Still, the most common cause of death in people with chronic spinal cord injuries, is infection as a result of urinary tract infection that isn't looked after right away, as well as pressure ulcers that were not looked after, and respiratory infections.

A - And if those aren't dealt with quickly, then the person runs into greater medical problems so they wind up back in the hospital for a greater period of time because it takes longer to resolve the issue, which if it had been attended to urgently in the first place, would have saved time and money. To me, seeing





that happening was something that was really impressive. But that is not happening now and people are going to family doctors who really don't know or specialize in spinal cord injuries, and don't know the urgency of treating a spinal cord injury or a urinary tract infection

If someone gave you a magic wand and said you can change one thing today that's going to benefit people with spinal cord injuries, what would change?

O – A closer follow-up program where people with spinal cord injury could have easy access to attention, because when they run into problems they get sick fast.

A – I would agree – just access to medical and nursing attention on an emergency basis. On a drop-in basis. I mean, people with a spinal cord injury, they know themselves; they've been through the mill. They know that these certain signs or symptoms likely mean this, that, or the other thing. So they can come in and tell the individual – this is what I'm experiencing, this is what my problem was in the past, and that individual they're talking to usually knows their history and can deal with that quickly.

It sounds like what you're suggesting is, if there were a proper program there would be cost-savings because issues would be treated early?

O – A big problem with chronic spinal cord injuries is pressure ulcers. We need a comprehensive pressure ulcer prevention program. It has been designed but it has not been implemented because it is costly. But if we can prevent pressure ulcers, it will be cost-effective. It requires a lot of coordination; it requires psychological input - I don't think it can survive without psychological input – and that was certainly in the structure of the design of the program.

A – I don't think you're going to ever eliminate people getting pressure ulcers – it's going to happen – but if you can reduce the number of people that are getting pressure ulcers, and not being treated or taking so long to get to treat them, you're going to save a bundle of money. With all the changes that they're looking at and a new delivery system – how can you get some of this stuff going again? They realize it's something that needs to be addressed, but you're sitting there going through this quagmire of program change and you're trying to figure out, now how can we get some of these issues or problems or whatever addressed in this changed system? There doesn't seem to be anybody that is in charge that will be able to say “look, we're going to implement this. It just seems to be a whole bunch of people out there having meetings, but

there doesn't seem to be anybody that grabs the bull by the horns and says “okay, we're going to do this.”

O – The health care system seems to be driven by money and somehow we have forgotten about care of the patients and respect for the patients and love of people. That is somehow lost in our health care system, so we're not thinking about what it is that patients need to be able to go on with their lives after such a catastrophic injury. We're thinking about how many hospital days can we cut down, or when can we get this person out of the hospital? We're not looking at what's best for the patient, but we're looking at what's best for the health care system. And we're not thinking of the health care system as helping people – what's happening to this world if this is what our systems are doing?

And you know that filters down to the ward level. That filters down to the nurse or the unit assistant or whomever that walks into the room. They get that same attitude. They're forgetting about what it's like for that person in that bed.

A – You can see the change in the attitude of staff because it's driven from the top. You've got to meet your deadlines, and you've got to meet certain restrictions. So they're looking at all of these outcomes that they've got to reach rather than saying “okay, what is it that this patient needs and how can we address it.” They're saying “gee, we've got to get them out of here in 30 days or whatever.” As Orpha says, it filters down to the caregiver, whether it's a nurse or an aide, or even a doctor

I think the problem that I see with government policies is that they're looking at a short-term saving and if they can save themselves, for this year's budget, they've met their goal for this year. And then next year they go on again and say “okay, we've got to save some money.” Rather than saying “okay, this is a cost that over a period of “x” number

of years is costing a phenomenal amount of money. If we just put some more money up-front, in the long run, we're going to be saving money.” But to me it seems like they're looking for a short-term financial saving which translates into long-term increased costs.

It's hard to identify who has the wand in the system.

O – Something that Arn and I have struggled with right from the very beginning, before we were ever going together...Arn and I used to have long discussions about the fact that people were not being looked after in the way that they should, and people's attitudes toward others. We always seemed to be advocating for patients. In those early times, and I know that





when I was in charge of the spinal cord injury unit, that was my constant fight. I was always fighting my staff for the patients and so I didn't do well as an administrator. In fact, the staff disliked me as a result, because I didn't know how to do it in a proper way. But Arn and I have always had this struggle and all of our discussions on our way home from work have been that we felt that people were not being treated in the way that they should be treated. Often we would allow ourselves that time when we were driving home, and once we got home we had to cut that off, because it just goes on and on and it's very frustrating. So we always had to limit our time of discussion in that way.

Are you talking attitudes within the hospital or generally or both?

A – Both, generally...

O – Well, to us, the spinal cord injury unit is the one that we were looking at. But it is general and I think that having come from the Salvation Army Hospital where I trained, you see the difference in the different hospitals. So that certainly it did come from the top at the Grace Hospital, this caring for patients, which was always the main goal. Whereas here you don't hear that. You don't hear that coming from Administration and you should. Because if it doesn't come from there....

A – ...it doesn't come from anywhere. It's not going to filter down. It has to come from the top. We see it more because we work in the hospital. But also in the community you get all these other agencies now sprouting up and they're all trying to provide service; for what purpose? For money. They're in business to make money. They may or may not have the best interests of the client at heart, but the reason they sprang up is because it's a business. That seems to be even more prominent now even than before and it's ironic. Here's a lot of these service agencies, independent service agencies, springing up to make money and on the other hand, you've got the system trying to save money. And to me it's like two opposites. What's happening here?

I guess it's the belief that "for profit" is leaner, meaner and more efficient and gets outcomes.

A – Yeah, yet I don't know and I don't know enough about the system in the States. You hear a bunch of horrible stories about people not being able to get, whether it's medical attention or whatever, because they don't have the money. Yet the people who've got the bucks can buy the stuff that they need. Is that



Retirement = Fishing

what's happening here? It almost seems like it. If you've got the financial resources then you can get the services that you need because there's a whole bunch of these agencies that are willing to come out and help you if you've got the money.

O – If people would just put themselves in the place of the person that they're looking after, they would do it totally different. If they would think a little bit about what it must be like. But it's so lacking. And you see it everywhere. Not just in health care. It's everywhere.

A – Maybe it's something more systemic. You know, you go to a business to get the tires changed in your car and if you go into some place where they don't care, you can see it right away. Are you going to go back?

It's an issue of service.

A – Yeah! And it's the company that's going to put the tires on and care, and make sure you're safe and you're dealt with properly – you're going to go back to that person and you're probably going to save yourself time and you're going to have a happy customer. Today it seems like in this health care system that caring to get the things that you need seems to be lacking. I know we're saying this over again, but it's got to come from the top and it's got to filter down.

O – And the reason that we see that is because we've been in it so long and we've seen the changes. And it's hard as you get older to accept that kind of change. To see that, when you knew it when it was working well and then to watch the changes, it's harder as you get older to do that.

What do you want to say now at this point, just before your retirement, to people who would be reading this?

O – If everybody had to go through a spinal cord injury and suffer the consequences for a little while, they would certainly be treating patients differently.

A – If the people that are effecting the change had to live with a spinal cord injury or other catastrophic disability, for a period of time, I think then they would get a real education as to what is really needed because they would be on the receiving end. I think that's my closing statement: "walk a mile in my shoes."

If you would like to read the full interview, it will be available online at www.cpamanitoba.ca very soon.

Kris MacIver

by Dan Joannis

In many ways, Kris MacIver is a typical teenager. He plays video games, listens to rap music, participates in sports, enjoys hanging out with friends and watching action movies. And in customary fashion, characteristic of adolescence, he hardly ever wears a jacket during the winter and is rarely seen in the summer without his baseball hat – turned backwards of course. He's become quite a handful, and those closest to him are very thankful and appreciative.

At 14 years of age, Kris was injured in a motor vehicle accident while driving with friends in Cross Lake (approximately 130 km south of Thompson). The accident left him with a complete spinal cord injury at the T5-T6 level, and turned his world upside down. He spent several months at the Health Sciences Centre in Winnipeg for occupational and physical therapy, and returned to Cross Lake in December 2000 to live with his mother (Marilyn), sisters Allycia (20), Beatrice (14), Allysha (2), and younger brother Glenn (11).

It was not until October 2001 that I was first introduced to Kris, by CPA Rehabilitation Counsellor Virginia Mills, who suggested that I meet with him to discuss wheelchair sports and recreation. Kris had recently been readmitted to the Health Sciences Centre for a short stay, and I was hoping to establish a good rapport with him during that initial meeting. Unfortunately, the first encounter turned out to be a dismal failure. His spirits were obviously down and he barely acknowledged my presence, but he agreed to meet with me again. I returned to see Kris on several occasions, and although he remained cautious and guarded with me, he began to engage in brief conversations. Kris did express some interest in wheelchair sports, but he was eventually discharged and back in Cross Lake before we could arrange an introduction to any particular program.

Prior to his accident, Kris tried to keep himself busy with a number of different activities, including hockey, basketball, snowmobiling, hunting and fishing, but I was concerned that accessibility issues and lack of inclusive programs in Cross Lake would become overwhelming barriers. However, Kris was back in the hospital in January 2002, and while there was some initial trepidation, he was soon playing wheelchair basketball and wheelchair tennis, just two of the sports that he continues to be involved in today.

Following his discharge from hospital and a brief stay at a downtown hotel, Kris went to live with a foster family in Lorette (about 30 km southeast of Winnipeg) in May 2002. Although finding an appropriate and accessible foster

placement was challenging, it could not have worked out any better for Kris. Foster parents Nancy and Georges Bohémier are an incredible team and absolutely determined to provide the best possible home for all their foster children. And rest assured that keeping the Bohémier home running smoothly is a fulltime job - Kris, now 16 years old, is the 'big' brother, followed by Kevin (15), Wendelle (9), twins Willie and Geneviève (6), and Justine (20 months). Although he is genuinely happy with the current arrangement, Kris admits to missing his family and friends a great deal. As a result, Kris makes an effort to keep in touch with his family – he's traveled to Cross Lake two or three times in the last year just to visit, and he talks on the phone with his mother and/or father (Bruce, who lives in Nelson House) roughly twice each week.

Things have really come together for Kris in this last year and he's been able to take advantage of several opportunities. Last summer, he was selected to attend the Active Living

Alliance for Canadians with a Disability's Youth Exchange program, held from June 27th to July 2nd. He spent a week in Ottawa meeting and interacting with more than 50 youth with disabilities from across Canada, and participating in a variety of activities, programs and events, including sports, culture, heritage and leadership development.

In September, Kris started attending classes at Lorette High School and it appears that his batteries have been recharged. In fact, Kris' scholastic achievements in the first semester have earned him the Council for Exceptional Children's 'Yes I Can Award', given annually to students whose academic performance has

improved despite unusually challenging circumstances in their lives.

Outside of the classroom, Kris' accomplishments are equally impressive. In October, he was selected as a member of the provincial wheelchair basketball team that will be traveling to New Brunswick at the end of February and representing Manitoba at the Canada Games. In wheelchair tennis, Kris is competing for one of two positions on the team that will represent Manitoba at the Western Canada Summer Games, being held in Gimli and Selkirk later this year. And it appears that even the media has taken notice. Upon hearing his story, CBC Television decided to do a feature segment on Kris for a new program called 'Heroes', which will profile young Canadian athletes whose lives have been transformed through sport (air dates and times to be announced).

It's difficult to express the magnitude of Kris'





transformation during the time I have known him, but it's clear that his new environment and wheelchair sports were significant influences. Kris had little hope or direction in his life in the 18 months following the accident. All the sudden changes in his life had stripped away his identity and forced him to redefine himself in the face of his disability. He needed to make a connection and find a new place in the world, and he needed to feel like he belonged somewhere. A stable, supportive home environment and wheelchair sports have provided those opportunities, and today Kris is a vibrant young man with an eye towards the future.

Axle Grease

by Ken Davis

The next person that says to me, "Cold enough for ya?" is going to get my legbag emptied on his foot...Yes, it's been colder than a penguin's colon this winter, but at least we haven't had 10 feet of snow (Newfoundland) or horrendous ice storms (Moncton) or floods (Badger) or a drunken premier (pick one)....It seems that administrators at a California college campus were concerned about speeding wheelchairs, so they did the illogical thing and implemented a speed limit of 4 mph. So much for the old trick of "accidentally" hitting a girl and having her land on your lap so you can meet her....Botox injections into my bladder? Researchers are saying that 80% of everyone they've tested, have responded very well. Oh yes, the shots are for "over-active" bladders....The word 'Hero' has been tossed around a lot in the past 2 years, in reference to firefighters, police officers, soldiers and astronauts, but I wonder where society should draw the line between 'courageous' and 'Hero'? I know a few people in the disabled community that might fall into the 'Hero' category, if society's criteria wasn't so skewed....Positive disability developments in Manitoba: the new master's program in disability studies at U of M and a new disabilities office to open, with the purpose of improving communication with the government regarding disability issues....Make sure you ask about any new books in the CPA office next time you are in the area. There are some great ones....I've been using D-Mannose for a few months for bladder infections, but the jury is still out on its usefulness....Clint Eastwood didn't make any friends in the disability community last fall, when he testified against the Americans with Disabilities Act, and a new book recently released entitled, "Make Them Go Away" says that Christopher Reeves is doing much more harm than good to the disabled civil rights cause....Why do a large number of my disabled brethren hate bathing so much?....Handi-Transit reports that in the month of October, they had 1007 No-Shows! That's 1000 taxicabs waiting for people that never show. And then we have the nerve to complain about Handi-Transit....The restaurant of the month has to be 'The Peak' located in the downtown Radisson Hotel. Portions are huge, prices are reasonable, you eat free on your birthday and the view is not bad.....Just think folks, only two-and a-half months until skeeter season.

MEDIMART PHARMACY & HOME CARE SUPPLIES

**FREE PRESCRIPTION
PICKUP AND DELIVERY**

Phone **284-3759** to have your
doctor's written prescription picked up
and your medication delivered at
no cost - city-wide.

We deliver free everything we sell

**Bubble pack available
Home Care Supplies including
Bath Rails, Canes, and a full line
of Catheter, Medical and
Incontinent Supplies**

Pharmacists: Ken Kronson Louis Blanaru
Norma Hutchinson

756 Pembina

Fax: 477-4063

Wolseley Woodworking & Construction



Wheelchair Ramps designed and built to code

Wheel-in showers Accessible bathrooms

Doorways widened Home Modifications

MPI, WCB, VAC and Family Services friendly

667-5787 Mike Hladky (SMR, U of M)



Input Devices

by Regan Block

Is it getting so that your keyboard now has two good days followed by three bad ones? Does your mouse seem to always want to go left? Or maybe you just need a change to something new and improved. Fear not, as hardware manufacturers are relentless in producing better quality, more ergonomic, and multi-featured keyboards and mice.

Case in point is the Optical mouse. Its features include ease of use on virtually any surface, reliability (no moving parts for controlling motion), and easy to connect with either USB or PS/2 connections. Even most trackball mice are now optical, which ushers in a new era of reliability for those users of the older Kensington trackball mouse. Or you can go for the ultimate mouse which is a wireless, optical, trackball mouse from Logitech (www.logitech.com) that is rechargeable (batteries included). Don't forget that almost all mice now come with scroll wheels. Price wise, you are looking at \$30.00 for you basic optical mouse to about \$120.00 for a full featured Trackball.

\$100.00 is too much for a mouse, you say. How about an enhanced keyboard and optical mouse together for the same price? Both Microsoft (www.microsoft.com) and Logitech (who are the leaders in these fields) offer many different levels of combo packages. \$70.00 - \$160.00 are the ranges from a good package (wired) to an "Elite" package (wireless). The Enhanced keyboards these days have your now standard Multimedia controls (Play/FF/REW/Stop) and have plenty of shortcut keys that open up standard applications or you can program your own buttons. Please don't forget to check your hardware requirements before you buy. (Minimum Hardware Requirements: Windows 98, Pentium 133Mhz, 32 MB of RAM, 60MB of hard disk space.)

Now that you have your new hardware installed, it's time to head to the Control Panel. This is where the rubber meets the road. There are as many as 8 different options to adjust on your keyboard and mouse to suit your abilities. To access the Wizards in Windows XP or 2000 from the Start Menu, point to Programs, point to Accessories, point to Accessibility, then select the Accessibility Wizard and follow the instructions. For a full list of keyboard shortcuts, using Windows XP, from the start menu click Help and Support > Accessibility > Windows keyboards shortcuts overview > and finally Accessibility keyboard shortcuts.

Now let's check out some of the newer technologies for your computer. There is an input device termed a 'digital array microphone' that doesn't require a headset and has noise canceling technology that can pick up your voice up to 75 feet away. Go to www.andraelectronics.com for more info. There is a program that can understand up to 400 customized voice commands and requires almost no voice training. Go to www.realizesoftware.com. Using a web cam? How about using it as an input device. The people at www.cameramouse.com have just the testimonials and demos for you to test out this innovation at home.

Have you got some innovative ideas of your own? Or are you just stuck not knowing which way to turn. Either way, Ed Giesbrecht (OT) or Tom Scatliff (Rehab Engineer) at the Assistive Technology Access and Resource Centre (ATARC) on the main floor in the Rehab Hospital can help you out. There you can try various styles of current input devices, ones that have been modified and available software. You can also discuss your ideas and see if the staff can make them a reality. You can phone them directly at (204) 787-1757. One of the coolest things they were working on the last time I was there

was building the applications for the Palm Pilot handheld device. According to Tom, "There is nothing in a release state yet, but the ones we're working on are software & hardware alternatives to using the stylus and interface adaptations to make the devices easier to use." Boy, I can't wait to get one of those too. If you have any comments or feedback, please

email me at reganblock@shaw.ca.

Regan Block is a Test Analyst for Ceridian Canada Ltd. and a CPA Board Member.



340 Donald Street

Wheelchair Accessible

Ph. 947-1307

www.discreet.mb.ca

men's and women's wear,
adult videos, toys, oils and lotions,
and much more

'Keep the Romance Alive'

WE'VE GOT YOUR SUPPLIES!

PRODUCTS:

- ❖ Intermittent Catheters
- ❖ Condom Catheters
- ❖ Catheter Trays
- ❖ Texas Catheters
- ❖ Trojan Condoms
- ❖ Leg bags/Night bags
- ❖ Latex Tubing
- ❖ Cleaning Solutions
- ❖ Gloves
- ❖ Skin Bond Cement
- ❖ Sterile Lubricants
- ❖ Tapes/Dressings
- ❖ Compression Stockings
- ❖ Suppositories
- ❖ Disposable Bed Pads
- ❖ Reusable Bed Pads

BRANDS:

- ❖ Mentor
- ❖ Bard
- ❖ Sherwood/Argyle
- ❖ Convatec/Squib/Prosys
- ❖ MMG
- ❖ Hollister
- ❖ Alpine
- ❖ Johnson & Johnson
- ❖ Kendall
- ❖ Muko
- ❖ Smith & Nephew
- ❖ Harmonie
- ❖ Rusch
- ❖ Magic Bullet

Quick Relief

The Magic Bullet™ works twice as fast as other laxative suppositories, dramatically reducing bowel care time. It's specifically formulated in a water-soluble base that allows it to go to work quickly. Clinical trials have proven that the Magic Bullet can cut bathroom time in half, saving valuable time for both user and caregivers. Effective January 1, 2001, **The Magic Bullet™** is covered by NIHB (the Non-Insured Health Benefits Program) for the treatment of constipation in people with Spinal Cord Injury.



WE CARRY A COMPLETE LINE OF HOME HEALTH CARE PRODUCTS

To order call:

THE ACCESS STORE.

"MANITOBA'S ACCESS SPECIALISTS"

(204) 589-8955

or

Toll Free: 800-670-1670

**** Coming Soon ****

Online Ordering

mysupplies.com



Oh Baby!

by Monica Desjarlais

When Ken Davis called and asked if I would write an article for Paratracks, he specifically said, “Monica, what’s it like being a new Mom? What’s a typical day? Are you tired? Weak? Silly?..” Well, the answer is, “Yes, absolutely, all of the above.” As a matter of fact, his request for an article couldn’t have come at a more interesting (and challenging) time. She walks!

At the ripe old age of nine and a half months, Miss Emily Faye Desjarlais decided she would take her first few shaky steps. There is nothing like a Christmas tree full of lights to get you motivated to be mobile! Being the curious person I am, I looked up “walking – early” in one of my many childcare books. It explained that early standing and early walking (assisted or unassisted) won’t lead to bowleggedness or any other physical problem, and in fact, both standing and walking are beneficial, as they exercise and strengthen some of the muscles used in walking solo. Great – nothing to worry about, good for Emily! Then it goes on to say, “so as long as your back holds out, let her walk to her legs’ content.” As long as my back holds out, hmm – I thought, I wonder how long that will be.

Really and truly, the biggest ongoing challenge for me has been the sheer physical demand on my back and the energy level that caring for an infant demands. From bathing, to nursing, to trips to the high chair, in and out of the crib, and bending over car seats, I have put my abilities to the ultimate test. Lucky for me (and for the baby), we have an excellent support network in our immediate surroundings.

My family often comes home from work to no supper, laundry piled high, and toys strewn all over the place. It’s a sure sign that the day was one in which mom and baby moved from one activity to the next, leaving a trail of destruction behind. Unlike other moms, when the baby is napping, I never quite seem to get to the looming housework. It’s difficult enough to get to my regular (pre-baby) back care routine, which includes at LEAST 20 minutes of heat application, followed by half an hour or more of stretching, strengthening and yoga. Now all I get is a few twists and back bends DURING a 10-minute shower...if I’m lucky! It’s also essential for me to find time to practice the relaxation techniques I use to help control painful neurogenic spasms. Although many medications are safe to use while you’re nursing, anti-

inflammatory medications are not advised, nor should nursing mothers overdo it with pain medications or sedatives. As a result, I’ve had to explore alternative methods of pain management like visualization and meditation. Sometimes, I just need to get prone and stay off my feet for a little while and conserve energy for the rest of the afternoon. Laundry? Dishes? Vacuuming? Prepare supper...rarely. I really hate to sound like I’m complaining and I do enjoy every moment with the little princess (yes, even at 3:00 a.m.), but there really isn’t time to “do it all.” Yes, there are millions of mothers that “do it all” without complaint, but the reality of the fact is that those millions of mothers don’t have spinal cord injuries.

As a person with an incomplete injury, it took me a long time to see myself as an injured person and I spent many years fighting the realities of my limitations. As a new Mom, understanding my condition and pacing myself accordingly, regardless of attitudinal barriers has become of utmost importance. It took a very long time to understand and come



to terms with the nature of my injury and to learn the fine art of pacing. There’s nothing like having a baby to throw a major curve ball into the delicate balance you’ve created for your life as a spinal cord injured person. Talk about major changes! From weight gain to hormone changes, to feelings of elation and utter awe of the new life you created, to recuperating from major surgery (Emma arrived via an emergency C-section), to sleep deprivation, to cabin fever...you

name it, it happens in those first months with a newborn. It’s impossible to maintain your balance and you have to find it all over again, taking the time and care to include your little one in the search for balance in your life as a new mommy.

I need extra help. That’s hard to admit and a harsh reality to live with for me. Because I have incomplete paraplegia, the reality of the situation is that my husband and close loved ones end up taking on quite a bit of the load. After one particularly difficult week, I began to research programs that assist moms with disabilities. I quickly discovered that there isn’t a single program for moms with disabilities in the entire province of Manitoba! I was appalled by the huge gap in service in this area and so I pressed on. I was referred to several agencies that told me, “that a request for application of this nature to their program for support services was inappropriate.” There seem to be lots of programs for parents



of children with disabilities or programs for people with disabilities, as well as programs for low-income families, teenage parents, and even for people who want to learn effective parenting skills, but no programs for people like me.

I found it strange that there was no service program exclusively for parents with disabilities who need support with the physical demands of independently caring for a young child and maintaining a home. I was told that the individual's family is expected to do all the extras and that there are no provisions for helping people maintain and assert their independence in parenting. If you're not flat broke and you feel you need an extra pair of legs or a healthy back, you must hire somebody or depend on friends and family. If you're lucky – the neighbor's teenage daughter will come over and give you a hand with 'out of control housework,' or won't mind stooping over a 10-month-old while she walks in circles around the house for hours on end. No service provider is willing to help cover the gaps. Needing extra help and not having an option as to how to best fill that need (ie: whether or not to hire a nanny or ask family to do what I would otherwise do myself if I were able) seems to impinge on my desire to care for my child as independently as possible. I believe that part of the psychological difficulty of having a disability is reduced ability to exercise choice and have control over the affairs of one's life (whether real or imagined) – and I was angered by my discovery of the lack of support services.

Surrounded by good supports has been key in helping my transition into motherhood and Emily's first year an incredible success. Certainly there were times that I wished I could "do it all," but in the end, I would really be doing Emily an injustice because she would have a very tired, very cranky and very unhappy mom. And you know what? Your baby loves you just as you are regardless of what you can and can't physically do. Plus, they don't seem to notice that there aren't any clean coffee mugs. So, focusing on what absolutely HAS to get done and what we can ELECT to do and then organizing our days around that is how we cope around here. So what if there's some dog hair on the couch – I'll teach Emily not to

eat it. So what if the recycling is piled so high in the kitchen that I can't see over it. That's what baby gates are for. So to all those moms with SCI out there who probably do "do it all" and more – you go girls! And to Moms who are having a tough time managing – take the time to develop good social supports and never be afraid to ask for help. And to women who are thinking about becoming moms – I wish you the best of luck and hope your experience is one of great wonder and joy.

Trying to Make a Difference One Step at a Time

Hi, my name is Ryan Sturgeon, and I am a 20 year-old incomplete C4/5 quadriplegic. When I was 16 years old and going into my senior year of high school, I had a diving accident that changed my life forever. I had just got my driver's license and I was working part time to save up enough money to buy a car. Throughout school I enjoyed sports, working out and I was very adamant about weight training. I even had hopes of maybe becoming a personal trainer one day.

After my accident, I was initially paralyzed from the neck down and was told I had little chance of ever walking again. I spent the next six and a half long months in the Health Sciences Center, slowly recovering, learning how to sit, feed myself, and walk all over again. I was inspired by all the support I received from my family and my friends, and I was determined to not let my injury control my life.

At last it was time to leave the hospital, but now I had a whole new set of problems; I was without a job, a driver's license, or a future career. Through hard work and support from CPA I was able to get my life back on track. CPA helped me through times of uncertainty and hardship, and whenever I faced new challenges or had needs I was unable to deal with, CPA was able to guide and support me.

On Saturday June 21 of this year, I am holding a 'walk and wheel' event for CPA, called, "Walk'N Roll". This event will be held on the grounds of the Riverbank Discovery Center in Brandon, starting at 10:30 am. Each person will collect pledges, and then attempt a full lap around the paved Discovery Center walking path (approximately 2 km). Prizes, refreshments, and entertainment will follow the 'walk and wheel' event.

My goal is to promote community awareness, while raising funds for CPA services in the Brandon and surrounding area. One of my future goals is to bring a greater CPA presence into Brandon and area – perhaps through establishment of a CPA office. I hope all CPA members will be able to come out and show your support!

For more information, or to get involved, please contact me at (204) 728-5990 or e-mail me at _appollo@westman.wave.ca.

Therapeutic Functional Electrical Stimulation: New tricks for an old dog?

by Dr. Kris Cowley

Functional Electrical Stimulation, or FES, has been around for quite a few years. It started to gain popularity in the research world in the late 1980's, but it wasn't until the late 1990's that the evidence for some of its more profound positive health benefits really started being published in research journals. There have been hundreds of studies reporting on the benefits (or lack of benefits), of having spinal cord injured subjects stand, walk, cycle, and even row, using FES.

FES works by directly stimulating the muscle nerves in the limbs, by applying electrodes to the skin over the nerve of interest and applying a very small current through the electrodes to activate the nerve, which in turn, gets the muscle to contract. In order to get paralyzed subjects to stand, walk, cycle or row, several different muscles must be stimulated in a particular sequence, often using sensors and computer-controlled feedback to coordinate the activity of the different muscles and so that the subjects aren't inadvertently injured.

In this article I am going to limit my overview to some of the therapeutic benefits of FES rather than discuss FES that has been used mainly to restore a function, such as walking (although using FES for walking may also have some therapeutic benefits). Other uses for FES include restoring some hand function to quadriplegics, ie. , 'the glove', developed in Edmonton, Alberta, by Dr. Richard Stein and his team.

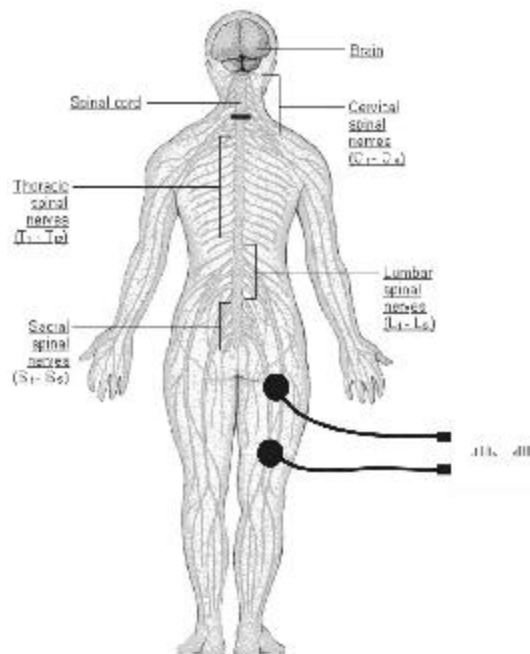
How does FES work?

After a spinal cord injury, the spinal cord is damaged and so the messages from the brain cannot get through the spinal cord and an individual may no longer be able to voluntarily get his/her muscles to contract below the level of the injury (so for a person with a C6 level injury, he/she will not be able to contract the stomach, back, legs, etc.). However, as long as the motoneurons supplying those muscles are not damaged (e.g., by a syrinx in the spinal cord), those muscles can still be made to contract. So, FES works by stimulating the nerves supplying those muscles directly, bypassing the spinal cord completely. This cartoon shows the back of a person, his brain, spinal cord and peripheral motor nerves. The surface electrodes have been placed over the nerves supplying his hamstring

muscles so that a small stimulating current would cause his leg to bend at the knee.

Although common sense would suggest that if you can get paralyzed limbs moving, you will increase circulation and build up muscle mass. And if you build up muscle mass (say on your butt) you will get increased padding where you sit and decrease the chance of getting pressure sores. Similarly, if you increase circulation when you stimulate the muscles, maybe the effect will help to speed up repair processes (like wound healing) that depend in part upon blood circulation to bring nutrients to the wound and take wastes away. Other effects, such as any cardiovascular fitness benefit or increased bone density may be less readily apparent, but worth testing. Although these benefits or positive effects might seem like common sense, FES-induced activity might just as likely damage muscles and have no effect on circulation to the muscles and/or limbs being activated by FES. Maybe there is no effect on cardiovascular fitness or bone density as a result of FES-induced physical activity. Why? Because maybe we need an intact nervous system to increase blood flow to the muscles, and get the heart beating faster, and maybe the FES-induced activity is not strong enough to increase bone density (among other reasons). So, these possibilities needed to be tested.

Before I begin talking about the FES studies, I want to raise one other issue. What about diabetes and glucose intolerance as a secondary complication of SCI? Huh? Well, it turns out for several reasons (mainly related to inactivity), persons living with spinal cord injury are much more likely than the general population to get diabetes. Also, many people with a spinal cord injury show decreased glucose tolerance (and increased insulin resistance), which is thought to be related to later developing type II diabetes (and heart disease). A study by Bauman and Spungen in 1994, did tests on persons with SCI and showed that 22% had diabetes (compared to 6% in non-SCI controls). Further, they found that 62% of quadriplegics, and 50% of paraplegics had impaired glucose tolerance (compared to 18% of controls), although they did not yet have full-blown diabetes. So, why am I bringing up this pleasant little piece



of trivia? Because, it turns out that in the able-bodied population, physical activity can decrease the risk of getting diabetes and it can increase glucose tolerance (which is a good thing). The question becomes: can FES-induced activity reduce the risk of getting diabetes? Can FES-induced activity improve the impaired glucose tolerance and insulin resistance situation seen in the majority of quadriplegics and paraplegics?

Well, the short answer is . . . yes. Yes, FES-induced activity can increase muscle mass, improve cardiovascular fitness, improve the glucose tolerance and insulin resistance situation, and increase bone density of chronic (long term) spinal cord injured subjects, and is associated with an increase in blood flow to the legs. Because of space limitations, I will not discuss the details of the FES-induced blood flow increases, or the cardiovascular fitness improvements.

What is a REGYS Cycle?

The REGYS (formerly ERGYS) is a modified reclining leg cycle that has been adapted so paralyzed subjects can pedal the cycle when their legs are activated using FES. Three muscle groups of each leg are stimulated in sequence using surface electrodes [the gluteal (bum), quadriceps (thighs) and hamstrings (back of the leg between the knee and hip)] so that the legs pedal the REGYS cycle (pictured below). Sensors are located on the pedals and a computer controls the intensity of the stimulation to the legs depending on how fast the person is cycling compared to how fast he/she is supposed to be cycling. The resistance of the REGYS cycle can be increased as the strength of the subject's muscles increases.



Continued next issue.

Manitoba Paraplegia Foundation (MPF) News

MPF Trustees:

*Doug Finkbeiner, Q.C. (President)
Arthur Braid, Q.C. (Vice-President)
James Richardson Jr. (Treasurer)
Honourable Mr. Justice Robert Carr
Isabel Auld
George Dyck
Lawrence Cohen
Dr. Lindsay Nicolle*

MPF funds go to work in four main areas: special projects, product testing, research and direct aid to persons with SCI. CPA thanks MPF for its continued support to improving the quality of life of persons with spinal cord injury.

MPF has approved several requests for financial support during the past few months. Below are a few of the highlights.

In September 2002, MPF provided funding to assist with the purchase of a wheelchair and walker for a newly injured client who was in a financially tight transition time of his recovery.

In December 2002, MPF approved funding for travel costs associated with training a Manitoba physician in performing Botox injections for use in bladder hyperreflexia in Manitoba, conditional upon Manitoba Health approval.

In December 2002, MPF provided funding for conference registration for a member of the R4 Spinal Cord Injury Team to attend the "Comprehensive Case Management" conference in Kelowna, BC.

In January 2003, MPF provided funding to cover half of the cost of a lift for a CPA client's home, with the provision that the lift be donated to CPA when the client no longer requires it.

In February 2003, MPF provided funding to CPA to purchase fitness equipment which will be loaned to a CPA client for their use. This equipment (wall pulley) will be returned to CPA when it is no longer required.

MPF Has A New Website

Manitoba Paraplegia Foundation Incorporated has launched a new website and it is worth checking out. It highlights basic information about the Foundation, including recent news articles as well as listing numerous activities the Foundation supports. You can check it out at www.cpamanitoba.ca/mpf/



You too, Can Take a Hike!

by Steven Fletcher

Ever dreamed of going hiking? The kind of hiking where you go up a lonely mountain pass, down through a misty valley, over fallen logs, or through thick knee-high mud? Any obstacles that anyone is likely to ever encounter are now surmountable for people with even the severest of physical disability.

Allow me to introduce to you the *TrailRider*. The *TrailRider* was designed to overcome these barriers and more. Powered by two able-bodied team-mates, the vehicle requires no accommodations whatsoever and can easily negotiate the most rugged trails; it is minimally invasive ecologically in that it is non-motorized and travels on one pneumatic tire. Described as a high-tech cross between a rickshaw and a wheelbarrow, the *TrailRider* is suitable for a wide range of users from special needs children to seniors to aggressive sports enthusiasts looking for adventure.

Hiking in the Canadian Shield was one of my greatest passions before a car accident left me completely paralyzed from the neck down (C4), seven years ago. It seemed that my hiking days were over. My love for the outdoors and my inability to access our great Canadian wilderness were two of the great spiritual losses I felt after my accident.

However, while in Victoria, British Columbia for Mobility Cup – a sailing regatta for the severely disabled, (another great program, for more information visit www.disabled-sailing.ca) I met a couple of quadriplegics who were planning a weekend hiking trip up a mountain pass. I immediately assumed that they mis-spoke and were going to be using a cable car, helicopter, or a road. However, I was wrong - big time. They were hiking on the same kind of trail that everyone else would use to hike up a mountain.

How could this be possible? Even though my new friends from BC were telling me that it was indeed possible for me to hike, I was very skeptical. However, I stayed in contact with them last winter and this past summer, I acquired a *TrailRider* to use. And it is true, it does work, and it works fabulously!

My first hike was in the Whiteshell on the McGillivray Falls trail, a favorite day-hike of mine before my accident. During



the hike, I can't tell you the emotions I felt as I saw lakes, waterfalls, and flora and fauna that I had dreamed about for six years. There they were, in reality, in front of me! This summer I went on more hikes culminating in a hiking trip up a mountain in Alberta this September. It was fantastic!

The designers of the *TrailRider* have thought of every problem from transferring into it, to keeping warm and dry

during a hike. In fact there is even an Outward Bound type of experience called Access Challenge which occurs each year in British Columbia where teams of five (four volunteers and the individual with the disability) race up a mountain over a long weekend. Yes, they figure out how to go back-country camping too. For more information on Access Challenge or the *TrailRider* please visit www.reachdisability.org.

The experience of hiking again was so profound that I want other people in Manitoba with severe disabilities to have the option of going hiking. Reach Disability, in British Columbia and myself are teaming up with other dedicated volunteers to set up a disabled hiking program in Manitoba.

Our goals and objectives are:

1. To introduce people with significant disabilities in Winnipeg to the potential for wilderness access that now exists through the development of the *TrailRider* access vehicle.
2. To demonstrate the importance of establishing a community-based, volunteer-driven hiking program specifically for people with significant disabilities, highlighting the health and societal benefits that result when barriers to access are removed
3. To provide a starter-fleet of *TrailRiders* for the future use of Winnipeggers
4. To identify and support key individuals within the community who are prepared to establish an ongoing wilderness access program for people with disabilities in Winnipeg.
5. To create general awareness throughout the community that complete access for **all** citizens is possible.

I wish to thank the Winnipeg Foundation for their generous



support in providing funding to begin a disabled hiking program in Manitoba.

If you are interested in hiking or wish to be more involved either as a volunteer or in the organization of the program please visit my website at www.stevenfletcher.com. On my site you will find more information about disabled hiking, how to get involved and my contact information.

Happy trails!

Acknowledgments

Reach Disability in Vancouver

Tetra Society of North America

The Winnipeg Foundation

CPA extends its sympathies to the families of the following loved ones who recently passed away:

Julia Sumner

Delbert Amiotte

Charlie Grover

David Epp

Edward Morgan

Grace Paisley

Angus Swan



Carl Champion: A Profile

While most people reading this magazine are familiar with spinal cord injuries and the individuals that have suffered them, not as many people are as familiar with the difference between a ‘complete’ spinal cord injury and an ‘incomplete’ spinal cord injury. With a ‘complete’ injury, the individual’s spine has been severely damaged, while with an ‘incomplete’ injury, the spine has only suffered a moderate amount of damage. The resulting injuries are obvious; a ‘complete’ injured person lives life in a wheelchair, while an ‘incomplete’ injured person gets to keep walking. Well, I have an ‘incomplete’ spinal cord injury (C7) from an accident that occurred just over five years ago.

I used a wheelchair for a short period of time, then slowly regained walking ability over the course of about a year. I obviously noticed some big differences between life in a chair, and life as a walking disabled person, but perhaps the biggest difference was in attitudes from the public.

Before I explain, let me describe my situation.

A very large physical barrier for me is the lack of proprioception in my paralyzed leg. Most people (SCI included) don’t have any idea what that is or what it truly means in terms of normal functioning. My condition is known as Brown Sequard Syndrome. Most people believe that if you can move a body part, you can feel it. Not true. Because only one side of my spinal cord was damaged, my paralysis is on one side (left), meaning that today I have good movement in my paralyzed leg, but proprioception.

Because of Brown’s, my leg still feels exactly like it did right after my accident when it was still paralyzed. When I close my eyes, I can’t picture or feel that part of my body. This means that I must have my leg in my line of sight at all times when walking, but it’s even more than that, it’s not just about being able to look at it, but actually directing every step that I take. I need to be completely aware when I am walking, or I

fall. If I ever trip and fall while walking, it’s usually because I’m trying to think about something else while walking. The saying ‘not being able to walk and chew gum’ comes to mind.

Walking uses about 50 – 80% of my concentration depending on the surface I’m walking on. If people try to talk to me while I’m walking, it takes some real effort on my part to carry on a conversation. I usually end up giving short answers just to keep the flow of conversation, but its not really computing. This is an invisible battle that I cope with every day, but no one even has a clue until I tell them. Even then, most people don’t understand, especially when I tell them that I can actually feel things such as temperature, light touch, and pain in my paralyzed leg. Now that’s a mind blower! I can feel my leg, yet I can’t feel it.

The most frustrating part can be trying to get people to understand what is wrong with me. When I was still in a wheelchair chair, people would rarely ever ask, “what’s wrong with you?” I assume it’s because they look at the wheelchair as an explanation to the question, but because I look like an able-bodied person, people don’t have that visual explanation. They only see someone who looks ‘normal’, but not able to walk properly. Some people will actually take the effort to ask me about my condition, but then I have to explain about SCI, because no one knows what I’m talking about. I usually just say, “I have some paralysis in my leg,” but then people want to know ‘why?’ It’s at these times that I think, “if I was in a wheelchair, no one would ever ask me at all.” It’s not that I mind explaining, but I just think that people want to know, yet don’t care, all at the same time.

I feel that my biggest barrier is that people don’t care or have a clue about spinal cord injuries, other than what they’ve heard about Chris Reeve. Unfortunately, I’m sure that many people consider him a ‘vegetable’, but no one thinks much beyond that.



Barb Yake: Still Looking Great

My name is Barb Yake, and I'm a single-mother of two teenage girls. I own my own car and home, and I'm presently attending Red River College, taking an evening course to become a Health Unit Clerk. During the day I take care of our home and I study, while in the evenings, when I'm not at school, I drive my daughters to their activities, or I attend my Tae Kwon Do classes. Life is good, but it has been a 11-year struggle to get this far.

On June 5, 1989, I was on my way to my job at Northern Telecom (where I had been working for 10 years) when I had a car accident. In the accident, I fractured my neck at the C-6/7 level. The doctors were not optimistic about my prognosis, but I was. Within two weeks I began to feel pinpricks and I could just barely wiggle my big right toe. The doctors diagnosed me with Central Cord Syndrome, meaning basically that part of my spinal cord takes over for the damaged part. After five months of hospital stay and countless hours of rehabilitation, I walked out of the hospital, without the use of a cane. I was now deemed a walking 'incomplete' and I looked great!

When I returned home from the hospital, my daughters were 3 ½ years and 19 months old. I took on my new role as homemaker, wife and mother, and we hired a home-care-type service to help out a few hours a day, but that didn't work very well. I used Handi-Transit to get to physiotherapy, as I was still not permitted to drive, but this was an extreme exercise in patience. I learned to hide my catheter, gloves and lubricant for my neurogenic bowel and bladder, and I learned to hide my not so perfect hands that looked arthritic and gnarled, with long sleeved shirts. I also learned that as long as I moved slowly and carefully, no one noticed that my left leg dragged or that I frequently lost my balance or that I looked like I had a carrot up my butt! But I still looked great!

The next 18 months were eventful, starting with my daily therapy as an out patient at the Rehabilitation Hospital, followed by a period at the Refit Centre, where I tried Tai-Chi until the instructor made fun of my crooked hands, forcing me to quit. I then tried aqua-size, aerobics and jazzercise-size, followed by a period of trying the stationary bike, weight training and good old fashioned walking. A group of my girlfriends got together to form an exercise club where we did aerobics to Richard Simmons and Jane Fonda, and in between I had relapses, so it was back to physiotherapy and massage therapy.

Fatigue plagued me. I wasn't sleeping at night because of spasms, while muscle relaxants were not helping. Stool softeners were making me gain weight, yet I was still always constipated, while I just couldn't seem to settle into a healthy bowel routine. I was irritable and finding it difficult to adjust to being a stay-at-home mom. I was very unhappy, but I looked great!

Financially, I was receiving 65% of my salary, which was cost shared by CPP and Northern Telecom, as well as a very favourable benefit package. However, trying to get money for supplies and therapy from my benefits package became an art

form, as they really didn't know what "neurogenic" was, and why I required certain supplies. I'm sure they now know how many squares I use to wipe my bum!

I was forced to go to the doctor's office at least four times a year, getting insurance forms, disability forms and prescriptions filled. I also met once a month for about a year with my lawyer to settle my Autopac claim, and I was constantly in touch with CPP, Northern Telecom, Human Resources and CPA. Then I had to deal with Income tax; that took five long confusing years, trying to figure out just how much I should be paying.

During this time period, we built a house with all the services on the main floor and we were the general contractors. Oh joy! By the time it was completed and we moved in, I had a severe case of shingles and was on bed rest for a month.

After a year, I got permission to drive again. It felt great gaining some independence. Around 1993, Northern Telecom and CPA looked into the possibility of me returning to work. My husband was set against it and I worried that I wouldn't be able to handle it. I still wasn't sleeping, while my dexterity was still impaired and my left leg was unreliable. If I spent any amount of time sitting or standing, it caused stiffness and pain in my left side and between my shoulder blades. But hey, I looked great.

In 1995 Dr. Dubo introduced me to the Myofascial Pain clinic. After a series of treatments I was able to lie on my side without too much discomfort. Such a relief!

I continued to stay at home, but started to volunteer at my daughter's school, helping with lunch duty two days a week. For this I received a small gratuity. CPP demanded that I declare it as income, and I was afraid that I would lose my disability benefits. I was forced to get a letter from the school principal and a note from the doctor. I helped out at my girlfriend's dance studio giving out receipts, answering phones, making coffee and fielding dance questions two hours a week, while my girls danced. In return, my girls got a discount on their dance fees. Again I began to wish for something more.

I enjoy people and get satisfaction from contributing, but could I handle working every day? I had worked up a tolerance from all my self-appointed therapy, but I still had relapses where I would spend all day in bed after a sleepless painful night. I did some more volunteering for the Manitoba Dance Festival as an announcer and quite enjoyed it. I tried my hand at gardening, but ended up back at physiotherapy for back strain. I tried interior decorating in my house, then went back to physiotherapy. I needed to find a happy medium and not over do it.

In 1996, I joined a Tae Kwon Do centre. It immediately seemed to help my balance and stamina, so I dropped all other forms of exercise and concentrated on martial arts. CPA got me to take an aptitude and tolerance test and it seemed that I scored well on 'aptitude', but not so good on 'tolerance'. Since then, I've taken an adult education course to become a dental



receptionist, where I did well despite the lengthy time in a very hard chair. I took a computer course at SMD, and upon completion went back to tutor the next batch of students. I've been promoted to black belt status in Tae Kwon Do, bought and sold a house, and did some renovations in my new house. In 1998, around the time I was separated from my husband, I was diagnosed with bleeding ulcers, then treated and cured. I also lost 20 pounds, but gained them right back. But hey, I look great!

I guess what I'm trying to say, is that everyone is different with a different set of circumstances. If I had been forced to go back to work sooner, I could have quite possibly done so, but on the other hand, it is also possible that I could have fallen flat on my face. I have two teenage daughters to think of, so I can't afford to fail right now. I'm fortunate to have support, but what of the people who don't? I believe that if you take a person and gently guide them through rehabilitation and counselling, they will want their independence that much sooner and be more willing to accept the challenge of career change, or even lifestyle change. I'm still unsure if I'll be able to cope working full-time, but I'm now ready to try. I've built up this tolerance, because I've had the luxury of being able to dedicate 10 years to rehabilitation. I needed a lot of energy and motivation, so I cannot imagine working all day and then trying to do therapy, as well as look after a family and have anything left at

all for me. Five years ago I would not have handled it, but now I can sit for four hours, with periodic stretching, go to Tae Kwon Do three times a week and still manage day to day life. But that's me.

Before my accident I was a very active woman, into sports and fitness, and so I think that is why my recovery was so speedy, and we are talking about 10 years! The emotional trauma of the accident cannot even be imagined. You must walk a mile in my shoes and see if it hurts. People can't imagine the guilt that I feel when someone says, "What do you mean you have a disability? You're not back to work yet. You've got to be kidding! You look great!"

I don't appreciate not being given the choice to work or stay at home. Not being able to earn full potential or to be out in the world with my peers and friends. So, "NO," I don't want to milk the system, I just want to be like everyone else and feel I'm a part of society. I know I have something to offer. Yes, it is true there are always some who may actually prefer to live off the system, just as it is also true that not everyone whose disability you cannot see wants to live off the system.

People must be seen as individuals with individual sets of circumstances and not be lumped together as malingerers.

I'm sure I'm not one, and besides, I look great!



- Stair, Van and Porch Lifts
- Manual Wheelchairs
- Power Wheelchairs
- Scooters
- Lift Chairs
- Wheelchair Ramps
- Specialized Seating Systems
- Bath Safety Equipment
- Commodes
- Incontinence Products
- Wound Care Supplies



On-site Service Department With Qualified Technicians

- SERVICE • SALES •
- INSTALLATION •
- REPAIRS •



865 Bradford Street, Winnipeg, MB • Phone: (204) 786-6786 • Fax: (204) 783-7496



Leisure and Incomplete Spinal Cord Injury

by Dan Joannis

Although the average number of new spinal cord injuries has remained relatively constant over the years, the ratio of incomplete to complete injuries has risen steadily in the last decade. But whether the injury is complete or incomplete, SCI can be accurately described as ‘catastrophic’ because the impact is sudden and devastating. Yet, when an individual with an incomplete injury recovers the ability to walk, the typical reaction from loved ones and sometimes even the medical/ rehabilitation team is to marvel at their good fortune. “It could have been so much worse,” they are told.

It’s no secret that the world was designed for upright, bipedal locomotion, so there is a distinct advantage for those who are able to walk. However, to suggest that an incomplete injury is somehow preferable to a complete injury ignores the fact that people with incomplete SCI deal with a different set of equally challenging issues, particularly when it comes to quality of life.

One of the most important factors influencing quality of life issues for all people, including those with a spinal cord injury, is leisure. Simply stated, leisure is what we do for fun, without external pressures, incentives or obligations. Leisure is directly related to our state of mind and not necessarily linked with a particular activity. Even if we are not consciously aware of it, we all have and need leisure in our lives. Some people find leisure in relaxing activities like yoga, reading or meditation, while others choose to participate in competitive sports or physically demanding recreational pursuits. Of course, the list of leisure options is long and varied, and since leisure is experienced in our minds, there is without exception ‘something for everyone’.

Nevertheless, the thought of returning to a pre-injury leisure lifestyle following an incomplete SCI can be daunting. Understandably, there are many questions and concerns, including: Can I still do the activity? Can I do it in the same way as before my injury? Can I do most activities safely?

One of the most common concerns for people with an incomplete injury, is knowing where they fit in. Due to the nature of their disability and their ability to walk, individuals with an incomplete injury frequently report feeling trapped or isolated, caught somewhere between having a disability and not having a disability. Do they ‘belong’ with people with disabilities or people without disabilities? To a large extent, the answer will depend on the individual and their level of comfort – what is appropriate for one person may not be for another. By definition, humans are social animals and need to feel accepted and part of a larger group, so each person will have to decide for him/herself which group is most appropriate.

There are a number of additional issues to be addressed

when considering a particular activity, including safety, equipment needs, fatigue or energy levels, and pain. These aspects must all be considered and should be fully discussed in advance in order to obtain the best possible results.

It’s worthy to note here that a very common misconception about wheelchair sports is that only wheelchair users can participate. Not true – most wheelchair sports employ an athlete classification system that assesses each athlete based on functional ability and ensures that athletes with a similar classification compete against one another. In team sports, however, each athlete is assigned a point value and the team must produce a line-up of players whose combined values do not exceed the given total for the sport. For example, in wheelchair basketball each team must have five players on the floor with a total classification value of 15 points or less, while a wheelchair rugby team has four players with a combined value of 8 points or less. The classification system varies from one sport to another, but generally speaking, each sport is designed to create a level playing field that encourages and promotes competitive opportunities for athletes with all types of disabilities, not just wheelchair users. In some cases, even people without disabilities are allowed to participate.

If you have an incomplete injury and are interested in getting involved in leisure, please feel free to get in touch with me directly, or with your community counsellor. I am available to talk and/or meet with you to help get the ball rolling. I’m also interested in hearing from anyone who would like to share what they have learned (good and bad) through their own personal experiences with leisure.

Legacy gifts to the Canadian Paraplegic Association...

...are future gifts, from your estate or life’s assets
...need not cost you anything today
...can provide current and future tax benefits to you
...are a means of perpetuating your legacy of caring
...help others, forever.

For more information, contact your local CPA
office, or call toll-free:
1-800-720-4933

Visit our website: www.canparaplegic.org



Canadian Paraplegic Association
Association canadienne des
paraplégiques
(Montreal), Inc.



P R O D U C T S

✳ 6-3166 Portage Ave. ✳ Winnipeg ✳ Manitoba ✳ R3K 0Y5 ✳
Ph. 204.832.9963 or toll-free 1.800.318.3044

“KEEPING CANADIANS IN MOTION”



✳ *All The Latest In Sport & Recreation Equipment*

✳ *New! Van Lifts and Home Accessibility Options*

✳ *New! Incontinence Management Solutions*



WATCH FOR “A DAY AT THE BEACH 2003”

July 18, 2003 (Rain Date July 25, 2003)

✳ **VOLUNTEERS NEEDED**

If not delivered, return to:
Canadian Paraplegic Association (Manitoba) Inc.
825 Sherbrook St., Winnipeg MB R3A 1M5

MEMBERSHIP APPLICATION



YES! Count me in as a member of the Canadian Paraplegic Association (Manitoba) Inc. All members receive “ParaTracks” CPA (Manitoba) newsletter, “Total Access” CPA National Magazine and voting privileges at the Annual General Meeting. Members also receive discounts at various health care supply stores – Stevens Home Health Care Supplies (special pricing for supplies & 10% off equipment), The Access Store (10%), Northland Home Health Care (10% off medical supplies), Disabled Sailing membership (25% discount) and student rate membership at the Joe Doupe Fitness Centre (\$91/year).

I wish to select the following category of Membership:

- | | |
|--|---|
| <input type="checkbox"/> \$15 - \$24 - Member | <input type="checkbox"/> \$250 - \$499 - Charter Member |
| <input type="checkbox"/> \$25 - \$99 - Supporting Member | <input type="checkbox"/> \$500 and over - Patron Member |
| <input type="checkbox"/> \$100 - \$249 - Sustaining Member | |

All Monies donated remain in Manitoba to support CPA (Manitoba) Inc. An income tax receipt will be issued for any amount over \$15.00. Sustaining, Charter and Patron Members will receive recognition of their generous contribution in the context of events such as our Annual General Meetings or in the programs of other CPA (Manitoba) Inc. functions.

Make cheque payable to:

Canadian Paraplegic
Association (MB) Inc.

Mail to: #211 - 825 Sherbrook Street
Winnipeg MB R3A 1M5

For more information:

Phone: 204-786-4753
Fax: 204-786-1140
E-mail: winnipeg@canparaplegic.org

PLEASE ENTER A MEMBERSHIP FOR:

Name _____
Address _____
City, Prov. _____
Postal Code _____ Phone () _____
E-mail address _____

New Renewal

CLASSIFIEDS



For Sale – Wheelchair Bags Custom made to fit your wheelchair. Reasonably priced. Call Marcia at 474-2039 for more info.

For Sale – Golden Technologies Power Lift & Recline Chair – dusk brown. Less than 2 yrs. old. Ex. cond. Pd \$1350, asking \$500 obo. Call Mary Anne at 837-6493.

For Sale – Electric Hospital Bed - V. Good Cond. \$800 OBO. Ph. Dawn Chartrand at 582-1135.

For Sale – 1988 Dodge Ram 350 fully equipped. C/W restraint straps, 2 removable bench seats, rear door wheelchair lift, PW, PD, Air and raised roof. Like new. Safetied. Only 44,000 km. Asking \$10,900.00 Phone: (204) 867-3361 anytime.

For Sale – 1993 Chev Astro Van - Ricon lift/Ricon Rotary seat base, hand-controls, tie-downs. Low mileage, no rust - super clean. Asking \$13,500 OBO. Call 888-3302

For Sale – 1988 Ford Wheelchair Conversion Van. 189,000 kms. Raised roof, floor lowered 4 inches, back seat bench (fold-out bed). Includes Crow River wheelchair lift (electro-mechanical). Q-strait tie downs and extras. Safetied May 29/02. Asking \$14,000. Call 885-6060.

For Sale – 1981 Dodge Ram B250 Van modified for wheelchair use. Vangator wheelchair lift. Power driver's seat, passenger seat on manual tacks. Raised sport roof with sunroofs. Annual rust proofing done by Rust Check. Record or original invoices of all work done since 1981 available. Photos available on request. \$5000 OBO. Phone (807) 467-0986.

For Sale – Electric hospital bed with removable side rails. Purchased Feb. 2002 – very good cond. Fitted with sliders, with optional casters provided. Foam mattress (rubber sheet and quilted cotton mattress cover included). \$1300.00 Contact Frances Harris at (204) 257-4938.