



Canadian Association
Paraplegic canadienne des
Association paraplégiques
(Manitoba) Inc.

MPF MANITOBA
PARAPLEGIA
FOUNDATION INC.

OCTOBER 2003

FALL ISSUE

PARATRACKS

Newsletter of the Canadian Paraplegic Association (Manitoba) Inc.



In this issue...

Botox, It Isn't Just for Wrinkles Anymore! A New Treatment for Overactive Bladder.
Regan Demystifies Palm Devices.

Plus... Walk'N Roll a Huge Success in Westman!!!



Meet Pauline Wood Steiman

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**paraplegic or tetraplegic*

Tansi, Hello, Bonjour!

I am Pauline Wood Steiman and I came to CPA June 23, 2003. I am the new Aboriginal Rehabilitation Counsellor who will be responsible for our Aboriginal clients in Manitoba and also Northern Ontario. This position is challenging and I hope that CPA will benefit with my experience to serve our clients.

My previous career was in nursing Northern Medical Unit, Residency Program University of Manitoba, in St. Boniface Hospital, and for a time I was on a surgical floor. I was employed at a Tribal Council as a Health Service Advisor for the Northern Community, developed programs and participated in National programs with the Federal Government, (formerly Medical Services) with diabetes programs and strategies. I was also co-chair for HIV/AIDS and was on various committees. During my work and travel I managed to complete my education, U of S with Health Care



Administration, Bachelor of Arts from University of Manitoba and Certification in Counselling, and volunteered in Community Clinics in Winnipeg. I was also medical interpreter for all four hospitals in First Nations language for the Assembly of Manitoba Chiefs.

My first experience with paraplegics is working with E-Flat at King George Hospital as a "candy striper". I hope that my work with our clients today will continue to be a challenge.

I have a husband of 30 years, 2 dogs and 2 cats. I enjoy outdoor activities, reading and writing.

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Here I am, World! (Ready or Not)

by Lorne Chartrand



As the last precious threads of soothing, muscle-warming sunshine unraveled and allowed evening's cold shadows to creep up the banks of the Assiniboine River on the first Sunday of October, the topic for my first editorial revealed itself to me. Change... resistance... fear...

Lamenting the loss of the warmth of the sun's rays, I realized that I was also mourning the final, tenuous hold on this past summer, a summer that will likely be my last as a student. My last to languish in the heat of the prairie sunshine whose end we shudder at and whose memory we cling to throughout the enduring, icy grip of every eternal winter. Education, it seems, has an end -- employment. As a career student, I often wondered whether the day would ever come where I would find the job that fit my training and compensated my scholastic efforts.

Frankly, I'm still not sure where that job is, exactly. For those that don't know me, I am a "high-level" spinal cord injured person. I'm also nearing completion of the Creative Communications program at Red River College. I went into the program intent on becoming a journalist -- a profession which was foremost in my plans even before I was injured on March 15th (ironically, the *Ides of March* for Shakespeare fans) 1995. I have a passion for print and radio.

Among other things, my injury produced a financial arrangement -- a modest disability pension -- in which I could, quite comfortably, never return to work. I could live a life of leisure; never again need I suffer the invasion of an alarm clock on my morning slumber. Heck, there would be no reason to ever stir before the crack of noon. Sound appealing? I imagine many of you who are subject to a workday schedule and run ragged by family, home, and budget, would look on this with at least a slight tinge of jealousy.

But then, during my first months in the solitude of my apartment at TenTen Sinclair, I also realized that such an existence would -- *for me* -- be a life of irrelevance. A bitter pill to swallow. Sure, I could self-educate myself; read all of the classic literature that most wait until retirement to enjoy -- but to what end? I had busted my backside for far too long in pursuit of a political science degree to let its only result be a finely tuned understanding of the weaknesses in the concept of civilization. I've always thought that I was somehow destined to make a difference.

So at the risk of losing my disability pension forever, I raged on. It's hard to know where the work world will go. My biggest fear is to go out into that world and find myself unable to withstand the physical endurance required as a full-time wage earner. Imagine the regret of returning to work in a stressful environment, putting up with pain and exhaustion without a way out. Once employed, would Canada Pension be there for me if I decided to rethink the situation?

Ultimately, my confidence in the communications program made the decision easier. Having endured the strain of it, the work world should be a piece of cake. I've learned more skills than I could possibly have imagined. The challenge will be to find the job that allows me to use the ones I most enjoy.

My entire point is that there is a risk as a severely disabled person who decides to take vocational training; the question of endurance, of not being able to withstand a full workday is a serious consideration.

For myself, the risk has been completely worth taking. I am confident that, somehow, I *will* be able to make a difference in this world. I will contribute. The assistance I've received from everyone at CPA has really made this possible. I know that there will be difficult times ahead though -- the pain and discomfort that one can feel, as part of living in a power wheelchair, is significant. I've already experienced the difficulties and humiliations that can arise in the working world, and I can tell you they are significant.

I chose advocacy as a theme for this issue of Paratracks, and I suppose I should tie this all together. There are many things that contribute to advocacy and one of the largest is information. It is much easier to foster change when we work together to educate and inform ourselves of the pitfalls that are out there. It is crucial to share our experiences. Change is far less apprehensive when we are prepared for it.

My hope is that you, as readers, will participate and share your thoughts, feelings, and experiences with all of us. By taking time to say, "did you know that this is happening?" we remove the surprise element for the next person that has the same experience. In so doing, we can approach change with less resistance and fear. I encourage everyone who reads these words to participate. Everyone can contribute.

Well, enough of my philosophizing . . . I'm looking forward to the challenges of bringing Paratracks to the world. One of my goals is to humanize the people that contribute to its publication. In this issue you will notice a picture of each contributor by the story title and a "byline" -- a short blurb about the contributor. Shifting my focus from school to the "work" of producing this newsletter is a change that I'm extremely excited about. It's a change I embrace.

Oh yeah, perhaps in the next issue I'll exhibit some of that "boyish charm" the illustrious Mr. Ken Davis accused me of possessing. His shoes will be big ones to fill...

Please address any comments to, the editor, Lorne Chartrand. Or, drop a line @:

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Botulinum Toxin for Treating Severe Bladder Spasticity

“What! You mean botox isn’t just for getting rid of facial wrinkles?”

by Kris Cowley PhD

After a spinal cord injury, often the voluntary control of the bladder is lost. Depending on the level and extent of a person’s spinal cord injury, ‘bladder management’ can range from intermittent catheterization to indwelling catheterization (when a person does not have enough remaining hand function to do their own intermittent self-catheterization). After injury, there is a wide range of outcomes in bladder function, from partial or complete voluntary control, to a bladder that never contracts and must always be emptied by catheter to one that is very spastic that empties on its own almost all the time (without any ability to stop it from emptying). This article will focus on treating one of the more ‘disabling’ complications in bladder function after spinal cord injury - severe bladder spasticity or what is sometimes called bladder hyperreflexia, or overactive bladder.

How does the bladder function before and after spinal cord injury?

In the ‘normal’ situation, the bladder, brain, and spinal cord work together so that urine is stored and expelled as desired. Figure 1 is a cartoon showing bladder control before and after injury (the letters and numbers in the figure are explained below). The bladder consists of two muscles.

- A. The **bladder wall muscle**, or detrusor (see top left of figure 1) stays relaxed while urine is being stored in the bladder. This muscle only contracts to push urine out of the bladder.
- B. The **bladder neck muscle**, or sphincter (see top left of figure 1) stays contracted (or flexed) all the time except when urine is flowing out of the bladder.

Before injury, when the bladder becomes full;

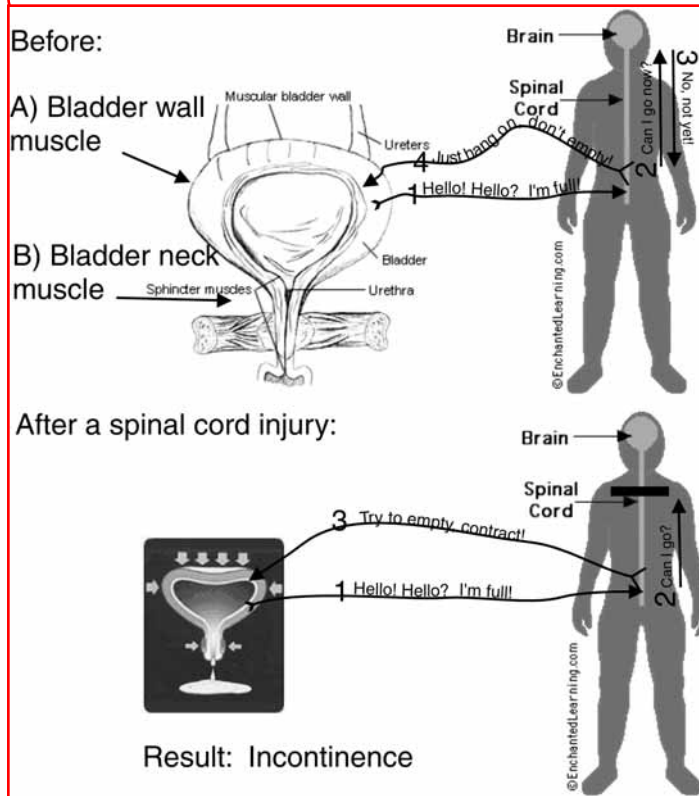
- 1) A sensory signal is sent to the spinal cord, and,
- 2) Another signal is sent to the brain.
- 3) The brain then tells the spinal cord to;
- 4) Stop the bladder from contracting and emptying until the person *wants* to empty their bladder.

When a convenient time for bladder emptying is found, the signal from the brain allows the coordinated relaxation of the bladder neck muscle (sphincter), and at the same time, the bladder wall muscle (detrusor) contracts to help push the urine out of the bladder (Figure 2 - right side).

After a spinal cord injury (bottom half of Figure 1), the bladder is often referred to as being ‘neurogenic’. Put simply, it means that it acts on its own, without input to, and control from the brain. Once the neurogenic bladder contains a certain volume of urine,

- 1) A signal is sent to the spinal cord, and,
- 2) A signal is sent to the brain but it never arrives (because of the injury). So, in the absence of control from the brain,

Figure 1:



- 3) The spinal cord tries to get the bladder to empty by telling the bladder wall muscle to contract or flex.

But without the brain to help coordinate the bladder muscles, the only thing the spinal cord does is get the bladder wall to contract. It’s like a balloon being squeezed and squeezed with a bit of glue keeping the neck of the balloon closed. If the contractions/squeezing of the bladder wall get strong enough, eventually the neck of the balloon will open and some urine will be pushed out of the bladder (and incontinence will occur). Sometimes, if the bladder neck doesn’t open, the urine will go back up the ureters to the kidneys (which can eventually cause kidney damage). After injury, many people will have some reflex bladder spasticity that can cause incontinence, but the volume or bladder capacity that this occurs at varies from person to person.

In extreme cases, the very spastic bladder may only hold a few ounces (or 90 - 150 ml), before the urine is involuntarily expelled and the bladder emptied (shown in the bottom half of Figure 1). Not only can this scenario be socially embarrassing for the person who has to endure it, but it can also lead to serious problems in kidney health. It is the extreme case of bladder spasticity that may benefit from botox injections, as outlined below.

What are the current treatments for severe bladder spasticity?

Up until recently, the only treatments for severe bladder spasticity were anticholinergic drugs or bladder augmentation surgery.

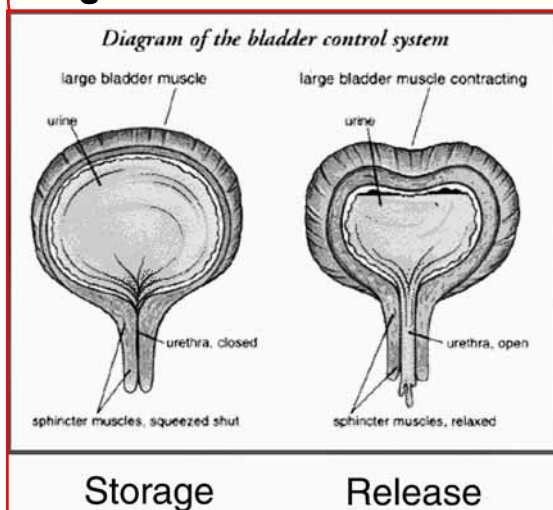
Anticholinergic treatment consists of taking drugs that stop unwanted bladder wall contractions. You may be familiar with anticholinergics such as oxybutynin, or more recently, detrol. After taking these drugs, bladder spasticity still occurs but the strength of the muscle contraction is weakened, hopefully to the point where incontinence no longer occurs. The reason the muscle contraction is weakened is because these drugs interfere with the signal from the spinal cord to the bladder that tells the bladder muscle to contract. The drawback with this type of treatment is that since the anticholinergic drugs are taken orally (in pill form), the drug goes to all parts of the body, including the brain, and they have to be taken at such a high dose to try to block the bladder contractions, they end up causing unwanted side effects that can limit a person's tolerance for the drug (e.g. dry mouth, drowsiness, constipation). In many cases, these drugs do not completely stop the incontinence.

In bladder augmentation surgery, a person's bladder is cut open and a piece of their intestine is then cut out and sewn into the cut part of the bladder to make a larger 'vessel'. Also, since the intestine is not able to contract like the original bladder wall, signals to the bladder to cause contraction don't do anything in the part of the 'augmented' bladder that is made up of intestine. Because of this, the involuntary signals that used to be enough to make the bladder contract and cause urine to be expelled are no longer strong enough and the person is no longer incontinent. The drawback of this type of treatment is that it requires abdominal surgery (and the six weeks recovery time) and if it works it means that a person will always have to use catheterization to empty their bladder.

So, Where does Botox fit in?

There is a new treatment on the horizon that may be quite useful for non-surgically and specifically blocking the bladder spasticity that causes incontinence. The treatment uses botulinum toxin to block the bladder wall contractions that occur in severely spastic bladders. Botulinum toxin (or Botox) is actually a food poison that has been refined for use in medical treatments. It has been used since the early 1980's quite successfully to treat many movement disorders. When used to treat spasticity by injecting it with a needle into skeletal muscle (say in persons with focal spasticity after stroke or SCI) the effect lasts for several months and then injections need to be repeated. More recently, it has been popularized by its use in

Figure 2:



cosmetic treatments for wrinkles (people have it injected into their face so they can no longer contract their face muscles and cause those unsightly wrinkles!?!). In 2000, the successful use of botox in treating severe bladder spasticity in spinal cord injured subjects at the Swiss Paraplegic Centre was first reported.

Basically, the study reports the successful injection of botox to stop bladder spasticity and restore continence to 19 of 21 patients. Before treatment, the average bladder capacity at which incontinence occurred was 296 ml, and all subjects experienced incontinence despite taking high doses of anticholinergics. After treatment, bladder capacity was over 480

ml (they reported it as 480 ml but they quit recording at 500 ml volume because they didn't want to over-extend the subjects' bladders). The report indicates that too low a concentration of botox was injected in the two unsuccessful subjects (they were treated with 200 rather than 300 units of botox).

The botox treatment has many potential advantages. Treatment can be done in a urologist's clinic; the entire treatment takes about 30 minutes and involves injecting small amounts of botox into several places in the bladder wall using a cystoscope. So, unlike bladder augmentation, botox treatment is relatively non-invasive (no surgery and related six week recovery period). Treatments only need to be repeated about every nine months, and the drug only acts on the bladder so there are no side effects throughout the body like those seen when taking anticholinergic medications.

The other advantage over taking anticholinergic pills is that the treatment works. So, whereas anticholinergic drugs may reduce bladder spasticity, many who take these drugs still have incontinence. In contrast, all those who received sufficient doses of botox remained continent until they required their next treatment.

One possible disadvantage of the treatment is the cost for the botox, which is about \$1200 per treatment or about \$1600 per year if you require new injections every nine months. Botox for treating spasticity is covered under some supplemental health insurance plans (e.g. Blue Cross). For comparison, one of the more recently marketed anticholinergic drugs (detrol) costs about \$134 per month or about \$1608 per year (if you take 2 - 2 mg tablets twice per day) and also may be covered under third party insurance (with special medical approval).

So, is botox treatment available in Manitoba? The short answer is no. At the present time, there are three urologists in North America performing the treatment. In Canada, the person currently doing treatments is Dr. Corcos in Montreal.

If you having any questions about this or other research related topics please feel free to contact me at 789-3305 or via email at kris@scrc.umanitoba.ca

Manitoba Paraplegia Foundation (MPF) News

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. Some of the highlights follow.

In June 2003, MPF provided funding to cover the cost of an eye examination and clothing for a CPA client who was recently injured and in the Rehabilitation Hospital. This client had no source of income as she had been living in a personal care home on a Reserve.

In July 2003, MPF provided funding for a CPA client to attend three workshops, which would assist him in preparing for a Graphic Communications certificate program at Red River College. Also in July 2003, MPF provided funding for a CPA client to travel from his home in Brandon to a meeting in Winnipeg regarding his spinal cord injury.

In August 2003, MPF provided funding for the cost of a transfer board

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for a CPA client. This special transfer board will prevent skin problems that have developed from using a standard transfer board. Also in August 2003, MPF provided assistance with education costs for two CPA clients attending university. These two students were on the Manitoba Department of Family Services vocational rehabilita-

tion funding wait list and required interim funding.

In September 2003, MPF provided funding for psychological services for a CPA client dealing with adjustment issues. Also in September 2003, MPF provided funding to assist with the costs of publishing and distributing the CPA (Manitoba) Inc. newsletter, Paratracks. This grant will assist CPA in continuing to meet its commitment to ensure that all of its clients and members receive this important information service.

Visit MPF's website at:
www.cpamanitoba.ca/mpf.
Applications for assistance are available through the website or by contacting the CPA office.

Winnipeg Accessibility Award Winners Announced

by Colin Mathieson

Have you ever been out-and-about and stumbled across an exceptionally well built ramp or any other such modification? Personally, I know it happens far less often than I would like. There are just so many builders and designers that are happy with building to the bare minimum standards. As I learned long ago, anyone can build a ramp, but building it properly is accomplished by few.

The City of Winnipeg has long been recognized as a pioneer for universal design and in its striving for equality in social policy. In addition to the city's adoption of the Universal Design Policy, in December 2001, which states that all city buildings will be constructed using universal design guidelines, they have also rolled out a new business award for accessibility. The award, called the Winnipeg Accessibility Award, is designed to give kudos to the people who have gone the extra mile in planning and implementing good building practices. The city has set up a committee whose role it is to identify those

people and businesses. The committee is not interested in holding anyone accountable; that's a task for the Human Rights Commission.

This committee is representative of all aspects of the community: designers, architects, consultants, advocates and service providers. Most members of the committee are USERS of the types of constructions being considered. Members took painstaking effort to come up with very precise application requirements. One thing that is very clear is that no matter how many applications are received, the winner must show that they have *exceeded* the building code. Universal Design elements must not be approached as an afterthought, but rather, would be a *leading* element in the design.

If, for some reason, there were no suitable candidates, the award would not be given in each of the categories. There are three categories for which submissions would be accepted: government project, residential design and any



*The Best Western Victoria Inn –
Best Private Business*



private business with ten or more employees.

And this year's winners are...

- The Best Western Victoria Inn – best private business.
- Cancer Care – best government project.
- Tranquility Place – best residential design.



*Cancer Care –
Best Government Project*

These three facilities have shown the initiative to include everyone and are obviously interested in giving back to the community. I know that I will utilize and recommend them when I have the choice, I hope you will too. This is a yearly award, so you may email the Access Advisory Committee on the City of Winnipeg

Web site, or myself, to nominate deserving facilities for next year.

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Or contact the Access Advisory Committee at:
 Phone: (204) 986-8345
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Colin Mathieson is a barrier-free design consultant for CPA and serves on the Access Advisory Committee. He is also a medal-winning international track and field athlete.



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"ANOTHER GREAT DAY AT THE BEACH"

Thank you to all CPA members who attended...

Plans are already underway for the

"4th Annual Day at the Beach 2004" July 16, 2004

THANKS AGAIN SEE YOU NEXT YEAR!!

Congratulations to Stephany Cholakis winner of The **DOUG GRANT** memorial award. The award is given to the person showing excellent determination and participation.



Walk'N Roll a Huge Success in Brandon/Westman

by Ryan Sturgeon

I would first like to thank all of the CPA members who were able to come out to the "Walk N'Roll" event held this year. The turnout was better than I had ever imagined, and the event was a huge success.

For all of you who don't know me, I'll just give you some quick background information. My name is Ryan Sturgeon, and I have been in contact with the CPA for almost five years now. I am a 21 year-old incomplete C4/5 Quadriplegic, and I broke my neck in a diving accident. The last five years haven't always been easy for me – initially I was completely paralyzed. Despite doctor's expectations I walked out of the hospital six-and-a-half months after my accident. The Canadian Paraplegic Association has continuously given me support and guidance when it comes to any challenges I faced.

At the beginning of last year I set out to raise money for others like myself in need, and to raise awareness for Spinal Cord Injuries and other disabilities. On Saturday, June 21st of this year, I held a 'walk and wheel' event for CPA, called

"Walk'N Roll". It took place on the grounds of the Riverbank Discovery Center in Brandon from 10:30 a.m. to approximately 12:30 p.m. We had a free barbecue and refreshments for all those who attended. CP Express provided live entertainment, while free massages were given out all around. We also gave away many great prizes including a brand new computer system, and everyone involved seemed to have lots of fun.



Participants in Brandon's "Walk and Roll" fundraising event hit the pavement.

Initially, I had hoped to see 100-150 people at the event, and raise upwards of \$10,000 for

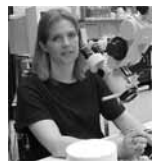
CPA. My expectations were well exceeded, as over 250 people came out and we raised over \$15,000 dollars to be used locally (within Brandon and surrounding Westman Area). The community has been enormously supportive and many of the businesses I approached were really eager to get involved. One day I hope to have a greater CPA presence in the Brandon/Westman area.

If anyone has any suggestions or would like to get involved next year please contact me at 728-5990 or appollo@westman.wave.ca.

RESEARCH

If you stand, please raise your hand!

by Kristine Cowley, PhD



I am interested in speaking to anyone with a spinal cord injury who uses a wheelchair for mobility but who also stands on a regular basis. So, if you use a wheelchair but are able to stand - either voluntarily, with the use of a neuromuscular stimulator (e.g. FES), a tilt table, or leg braces, please give me a call or send me an email. I am interested in finding out how often you stand, how long you've been standing and how long you've been injured. The reason I would like anyone who stands to get in touch with me is so I can see if there are enough people in Manitoba for a future study looking at some of the potential benefits of standing after spinal cord injury.

I can be reached at work at 789-3305 or by email at kris@scrc.umanitoba.ca

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The High Price of Gold

by Lorne Chartrand



Whenever he travels to an international competition, Colin Mathieson is usually hauling more metal for airport detectors on his return – yet this world championship and Olympic medallist goes largely unrecognized in his hometown. Colin recently returned from the Swiss Championships in Langenthal, Switzerland with gold as the anchor on Canada's 4x 100-metre relay team. After eight years of shouldering a huge financial burden to qualify for these events, however, Colin says next summer's Paralympics will be his last. Although he receives funding to represent Canada at international competitions, equipment, training, and other expenses leading up to these meets are his responsibility.

Stand back this is going to get messy. First, I'll need a bucket of red paint to emblazon a big, red, Superman "S" on Colin's chest. Why? Because I'm simply amazed that more has not been made of the heroic career of this short-distance wheelchair track-and-field athlete. Second, I will be making a lot of noise about the treatment of wheelchair athletes in general. This was supposed to be a feature about Colin's gold performance in Switzerland, but it's more than that – it's about what it takes to get there.

Now, I'm willing to admit that even able-bodied track and field athletes don't exactly dominate Canadian sports media coverage, but I'm wondering how many of our members had any idea who Colin was before a story was run on these pages last year. Compare that with names like Donovan Bailey and Bruny Surin – the able-bodied equivalent of wheelchair sprint athletes like Colin – and you get an idea about the differences in exposure.

Colin burst onto the track scene as a junior in 1989 with gold medal performances in a multitude of races. Between 1989 and 1993, Colin was the top performing junior athlete in Canadian wheelchair racing. In 1994 Colin qualified for the world championships with a Canadian record time in the 400-metre sprint, but at 15 years of age he was too young to

compete. Since then, Colin has been a force to reckon with. He has been the Canadian champion in one or more events from 1994 until 2003.

As a veteran of the wheelchair track circuit, Colin is gearing up for his swan song at next year's Paralympics in Greece. "I'm leaving it all out there, I'm going for broke... I don't want to have any regrets." Colin has qualified for the 100, 200, and 400-metre events.



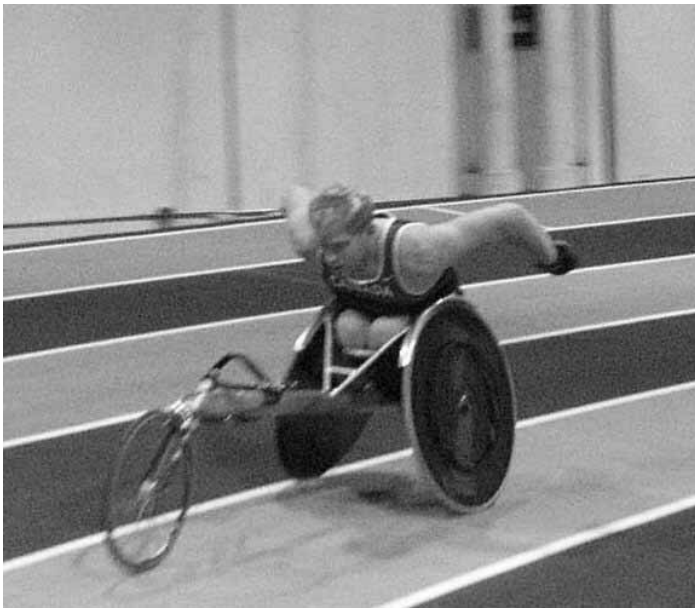
At the age of 24, with his times yet to peak, he's decided that he wants to pursue a "normal" life. Even though athletes can compete into their forties, Colin demonstrates a realistic perspective on athletics and life. "I think that you have about ten years where you can do without a lot of things, like job stability, relationships . . . you can only go so long without other meaningful things in your life. I'm right at that point, so it's a good thing that the Paralympics came around this year!"

Looking back at his career, Colin is appreciative of the support he has had from his family and the Manitoba Wheelchair Sports Association. What he wishes were different is access to mainstream audiences. A lack of exposure for wheelchair events translates into a lack of interest from young athletes,

and minimal corporate support. "I think right now we are seeing a real down-slide in participants, and I think it's just because nobody knows that we exist."

As a career athlete, the natural thing to expect is that Colin would consider coaching young athletes to carry the torch. "I'd like to see more emphasis on the kids, because they're the ones that ultimately will take my place." However, he's not holding much faith in that opportunity. "There is a lack of programs right now that I can even contribute to. Individual sports often take a back seat to team sports when sponsors look to donate funds – they want the best 'bang for their buck.'"

The cost of racing chairs is a significant barrier for young athletes who would like to get involved. "If I could I



stream events – plus the appeal of flashy sports chairs! If wheelchair events received more publicity, more awareness would be generated, and more young disabled persons would dream of becoming the next Donovan Bailey of wheelchair track and field – or better, the next Colin Mathieson.

Suddenly, I'm finding *myself* wanting to see more of these events. Someone get me in touch with Ron Maclean – perhaps he can put a bug in someone's ear at the CBC... What really needs to be done is to lobby the powers that be at the International Olympic Committee about including more wheelchair sports in the "regular" part of the Games. In the mean time, I know I'm pulling for Colin to win gold in Greece next year – a title defense of that medal is the only thing that he says will keep him in the game.

To quote The Crash Test Dummies; "Superman never made any money..."

would like to donate my old chairs, but because they fit so precise... It would have to be a perfect fit." Colin estimates the cost of an entry-level chair at \$3500. While only an increase in funding to wheelchair sport would change the landscape in Manitoba, Colin says, "in spite of the need for it [funding] we're just seeing more cuts. It's not a priority in government's eyes, yet the health, activity and well-being is?"

What seems to be missing is a commitment from mainstream sports *media* to cover wheelchair sport – during primetime. Broadcasters haven't realized that wheelchair races could have the same pumped-up appeal as the main-





ANNOUNCEMENT: *Wheelchair Curling & Sledge Hockey*

Manitoba Wheelchair Sport Association (MWSA) and the Manitoba Curling Association are exploring the possibility of developing a *wheelchair curling* program and would like to hear from anyone who might have an interest in participating in such a program. Likewise, MWSA is currently looking into potential funding to develop a *sledge hockey* program and would like to hear from anyone interested in playing. Please contact the MWSA office

by telephone at (204) 925-5790 or by email at mwsa@sport.mb.ca to indicate your interest in either program.



For more information on wheelchair curling, please visit the World Curling Federation website at www.worldcurlingfederation.org and click on the 'Information' link on the left, then click on 'Wheelchair Curling' under the 'Development' heading. For more information on sledge hockey, visit the Sledge Hockey of Canada website at www.shoc.ca.

PIT STOP 2003 – Prevention, Prevention, Prevention

by Monica Desjarlais



Many of us have heard of at least one program aimed at preventing injury due to drinking and driving. These programs are designed for high school students who are approaching the driving age (16) or who are new drivers. The programs often include information on the effects of alcohol and highlight the dangerous consequences of combining risky behaviors and motor vehicles. Some Paratracks readers may have spoken to T.A.D.D. groups (Teens Against Drinking and Driving), M.A.D.D. (Mothers Against Drinking and Driving) or the P.A.R.T.Y. (Prevent Alcohol Related Trauma in Youth) program at some point in their rehabilitation. The Manitoba government has its own approach to reduce the risk through the graduated driver-licensing program. Even Manitoba Public Insurance plays a part in the effort to raise awareness of the dangers of drinking and driving. In a small southwestern Manitoba town called Souris, a motivated Emergency Medical Services Unit at the Souris Hospital organizes what they call a PIT STOP.

On September 19, 2003, two CPA members whose injuries were caused by motor vehicle accidents (MVA) spoke to an attentive audience at the Souris High School. The PIT STOP 2003 speakers were impressed by the respectful audience and encouraged by the students' questions and reactions to the grim realities of living with a spinal cord injury. Other speakers talked about losing close friends and loved ones in preventable accidents. Best friends in the audience reached out to hug one other and the gymnasium was full of concerned faces after listening to one young paramedic recount the worst day she'd ever had as a paramedic. She attended the scene of an accident in

which a drunk driver had killed an entire family one early Sunday morning. That's when she developed her desire to speak to people about the consequences of dangerous driving. Young drivers were really visualizing what it might be like to lose their best friend, be responsible for ruining lives, or to never walk again.

Preparation to hear real life stories of lives affected by risk taking behavior began early in the morning with a mock car accident outside the school. Complete with the Jaws of Life, ambulances, lights and EMS paramedics, students were given quite a reality check. Later, the students had plenty of opportunity to try out ambulance equipment, disability equipment and to chat with paramedics about their jobs. By the time the speakers had their turn, it looked as though the high school students were getting the message...or were they?

Do programs such as PIT STOP really work? Do they really save lives and prevent injury? In one simple word, "yes" they do, says the National Center for Injury Prevention and Control. In fact, I'd suggest that prevention programs do more than just reduce injury in youth. I've known many spinal cord injured people who benefited from volunteering their time as injury survivor panelists. It gave them a chance to use their injury as motivation for young people to act responsibly...like a free warning. Speaking to prevention groups may not save every life, or prevent every unnecessary accident, but as the old adage goes...if I can reach just one kid – it's worth it.

Monica is a member of CPA and has been involved in a number of CPA initiatives over the years. She has become a regular contributor to Paratracks.



2003 CPA Merit Award

Presented to

Vocational Rehabilitation Services Directorate

In 1965 the Canadian Paraplegic Association (Manitoba) Inc. began presenting a “CPA Merit Award” to individuals and organizations in celebration of their outstanding contributions towards improving the lives of persons with spinal cord injuries and other physical disabilities.

The recipient of the 2003 CPA Merit Award, presented at CPA’s Annual General Meeting on June 18, 2003 was the Vocational Rehabilitation Services Directorate of Manitoba Family Services and Housing. The award was given to honour and recognize the Directorate’s commitment to persons with spinal cord injuries over the years. In particular, it is the people who have served in positions to fulfill the Directorate’s mandate who have made the difference. CPA commends Martin Billinkof and the entire department (Ernie Hasiuk, Norm Magnusson, Ray Hopke, Heather Ferguson and Bebe James, to name a few) for their collaboration and support of education and training for people with spinal cord injuries. These staff walked CPA staff through outcome statistics, development of service agreements, changes in policy decision-making, and special opportunity grant applications. As a result of this collaborative effort, CPA members have become educators, entrepreneurs, mechanics, lawyers, architects, counsellors, social workers, executive directors, accountants, government employees, and bankers, to name a few of the successes.

Hats off to the Vocational Rehabilitation Directorate – it has been with your tremendous support that CPA has been able to realize its mandate in the promotion of full participation and inclusion of CPA members in our communities. The presence of the Directorate will be missed as the Department of Family Services and Housing disbands it and transitions into an integrated service delivery model.



From left to right: Bebe James, Heather Ferguson, Norm Magnusson, Martin Billinkof, Darlene Cooper, Ray Hopke (Missing: Ernie Hasiuk)

Canadian Paraplegic Association (Manitoba) Inc.

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to

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in supporting persons with spinal cord injury

and other disabilities

to achieve greater independence, meaningful

lives and full community participation

presented this 18th day of June 2003

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Trip to St. Theresa Point First Nation

by Pauline Wood Steiman



In September, two staff members from the Canadian Paraplegic Association made a trip to the First Nation of St. Theresa Point, Manitoba to do a home assessment for a newly injured client. The purpose of the visit by Colin Mathieson and myself was primarily educational. We hope to use the experience to create awareness among medical professionals of the difficulties that our members in isolated First Nations communities face.

Difficulties encompass transportation, not only with planes that are small and not wheelchair accessible but also with water transportation and road access. The community is in a beautiful setting, full of lakes and islands. To get around the rugged terrain one needs to be healthy, own a vehicle and a boat. Finding employment is difficult for our members as it is throughout the community.

We were announced on the local TV station, and the reason for our visit was explained. Colin Mathieson was welcomed as an Olympian and invited to play basketball at the local high school to show his stuff!

Water accessibility was difficult, with small taxi boats that were not equipped for people with disabilities. The reason for taxi boats? The airport is on a small island and people have to cross the lake to get to the community. The boats do not have emergency equipment like lifejackets and life-saving rings, etc. The docks are in poor condition and not adjustable to the water levels.

The roads are not maintained because it is difficult due to the consistency of mud and clay, so it is slippery when it rains. There is some gravel and crushed stone but it doesn't last long due to heavy traffic on the road.

The housing is poor, without plumbing, running water, or even a bathroom or shower. The community is in the process of getting a water supply system set up. They have

a water treatment system and pipes for the water are in place, but they do not know how long it will take to be made operational.

Even though the First Nation is in the woodlands, access to finished lumber and material for ramps, docks and patios is very expensive. These products are shipped into the community. Delivery by freight is not reliable; there is no guarantee to have it delivered during the six weeks of winter when the roads that cross the region's frozen lakes are open. Primetime for these roads is January, February, and March, depending on the weather.

Families wait a long time for a new house.

In spite all the hardships the community people face, they are happy, it is their home and no transplant to other communities can bring them wealth. They wish to live in their own space, where they grew up. They have roots to "Mother Earth" which provided for them in times of need. No matter what they have or do not have, it is their home.

It is with great hope that our First Nations clients return home, to a community that has all of the amenities that the rest of our society enjoys, and to be independent from all bureaucracy.

Pauline Wood Steiman has recently joined the CPA Manitoba staff as the Aboriginal Rehabilitation Counselor. In her position, she contacts newly injured hospital patients and their families, as well as providing ongoing support and coordination of external resources.

Pauline can be reached at:
pwoodsteiman@canparaplegic.org



Colin takes to the court with high school students at St. Theresa Point

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

Don Watkins
Mike Empson
Robert Maloney
Katerina Sklavenitis



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

CPA Holds Aboriginal Feast to Celebrate “Broken Bodies, Broken Spirits” Project

This fall, CPA completed its *Broken Bodies, Broken Spirits* project, which delivered a total of four healing circle workshops between 2001 and 2003. The project, funded by the Aboriginal Healing Foundation, was designed to provide an opportunity to explore the negative impacts of residential schools on Aboriginal people with spinal cord injury, their families, and their communities. The Legacy of Abuse, through the residential school system, has damaged and complicated the recovery and rehabilitation process for Aboriginal people with spinal cord injury, and the healing circle workshops facilitated the start of a healing process for them and their families. Workshop details and participant responses were shared in previous Paratracks issues.

To celebrate the success of these workshops, CPA volunteer Roger Traverse organized a traditional Aboriginal Feast for participants, presenters, project co-ordinators and other special guests. CBC's Ian Ross was a wonderful emcee and entertained the guests with his popular 'Joe from



Winnipeg' segments. An excellent video documenting the residential school system was shown, followed by a hearty and delicious feast catered by Dorris Ross. The menu featured Manitoba pickerel, moose meat, wild rice, bannock, fry bread, vegetables, rice pudding, and fresh saskatoon berries with cream. Aboriginal musicians entertained guests during the meal. Workshop facilitators provided commentary about the project, and aboriginal artwork including dream catchers, animal hide drums with CPA logos, and colourful prints were given away as draw prizes. The evening ended with a prayer that was sung and drummed by Charlene Calder.

CPA wishes to thank Roger Traverse, and also Renata Marsden, for making this feast a success. While the event marked the end of Aboriginal Healing Foundation funds for the healing circle workshops, CPA hopes to obtain other support for more workshops that facilitate the healing process for persons with spinal cord injury, and their families and communities.

CPA Grows From Within

CPA would like to recognize and congratulate Darlene Cooper on her recent promotion to become the new Director of Rehabilitation Services. Darlene brings not only a wealth of experience in rehab issues and familiarity with the key players and organizations, but has displayed a real enthusiasm for the role such a director plays. Board and committee members have felt that enthusiasm in spades during the first meetings of this business year.

Hi everyone! For most members I need no introduction after 17 years in the Vocational Counseling position at CPA Manitoba.

I am, however, new to the role of Director of Rehabilitation Services. It is an exciting role and I have a great deal to learn. My predecessors made it look so easy. What none of us knew



was what *was* happening when that first office door was closed – I'm slowly learning.

The challenges are endless as we reorganize within the service division.

Change is good. Change forces us to review and re-examine our ways of doing business; retaining what has worked well and considering what might work better or differently, based on what is happening in other locations all over the world.

I look forward to an interactive role with our membership and I am always open to your feedback.

Regan Demystifies the Palm Device

by Regan Block



Most people say they want to own a home computer for the following reasons: contact lists, email, manage finances, write (and print) letters, surf the Internet, and games. But what happens when you're away from your home or office and you suddenly need that address, document – or you're just stuck waiting for a ride and you'd like to kill some time and play a game. Well, unfortunately, your PC is wired into a wall at your home, and while a laptop is a powerful machine, it is inherently expensive and power hungry. This is the very reason why the size and capability make Personal Data Assistants (PDA's) so popular.

Interested? Then read on.

The market is inundated with PDA's; with no less than six major manufacturers churning out new product every few months. The main difference between the current crop of PDA's is the operating system (OS): Palm OS by PALM and Pocket PC by Microsoft. Palm has been around since the beginning of handheld devices and has had great success with many third party developers creating 1000's of applications for this originating PDA. Pocket PC is a late arrival on the scene but is improving its market share amongst corporate users; mainly because of its bundled software that includes Pocket Word, Pocket Excel, Pocket Outlook etc.

Here are some feature you should consider when buying a PDA:

Memory – more equals the ability to store larger media files like MP3's, movies, and pictures

Rechargeable batteries – definitely more convenient than changing AAA's every month.

Color vs. Monochrome – color is great for almost everything but is much more expensive than black and white and sometimes harder to see in the daylight.

Bluetooth – a wireless interface that allows instant email, web browsing, and even cell phone usage.

The basic programs supplied with PDA's are pretty much all the same: contact lists/ addresses, calendars & alarms, memo pads and to-do lists, and beaming (an infrared port that allows users to share programs. More on this feature later).

Setting up a PDA.

Once you install the desktop software and drivers to your home PC, you just place your PDA into its cradle (base connect to your PC usually through a USB port) and you can start loading up your PDA with software and/or data. You can add the software that was included with your purchase

or buy software from the Internet (or get it beamed in!). Either way, once you have downloaded your new program, the desktop software will cue up the program and it will be installed the next time you sync up your PDA to you PC.

Using the interface

All PDA's use a combination of a touch screen, buttons, and menus to enter / retrieve information and to use the programs. The main input is the graffiti pad at the bottom of the touch pad. Graffiti is a handwriting recognition program that allows users to input text, numbers, and punctuation into the PDA without ever needing a 'normal' keyboard. Don't forget that lots of things like your contact list can be keyed into your home PC and uploaded to you PDA, so you are not limited to the just graffiti pad input. Dan, from CPA, notes that his main input method is the touch keypad in the GUI. He says that "it's quicker and simpler to (..to enter text) than taking out the stylus and writing out the letters individually."

If you're looking at getting an older style PDA like a Palm V or M series, the navigation buttons consist of 4 hot buttons along with 2 scroll buttons in the centre. More recent models have the same 4 hot buttons but also have a 5 position "wheel button," much like that of most modern DVD/satellite remote controls, which is much more powerful. One last note on the interface; if you are quite comfortable with the Windows user interface on your PC, you will be much more accustomed to a Pocket PC device – Start Menu, Icons, and names of some programs are a few examples.

Cool stuff

Here are some of the hot new features available on today's PDA's:

Bluetooth – (only on some models) allows a wireless connection to you PC or cell phone (if they are Bluetooth equipped as well) which will allow you to transfer files, send emails, or browse the web.

Multimedia – (on most models) software that allows you to view pictures, listen to audio files (MP3's), watch video, and record your voice. Definitely something to impress you friends with.

Games – older monochrome models have tons of fun games, like Tetris, that will keep you entertained for hours despite the lack of graphics. The newer color models with their brilliant use of 64K of available colors have some versions of some modern games like Age of Empires.



That's it for now, as next issue of Paratracks will focus completely on uses of PDA technology and some of the adaptive devices (and applications) for people with disabilities. In the meantime, do some homework of your own at: www.Cnet.com and click on Handhelds. You can easily comparison shop at the Web site and read reviews on all models. In case you don't, I will be upgrading from my Palm M125 soon, so my review may be in the next issue too. Until next time, happy clicking :)

Palm Pilot M130



HP IPAQ 1910



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We asked Bev: Competition for “the little blue pill?”

All about Noninvasive Sexual Stimulators

by Beverly Davis, RN, BN, CACE
Nurse Clinician



Editors Note: In August CNN announced Bayer and GlaxoSmithKline's new treatment for ED was approved by the FDA. The new drug will offer choice and perhaps will have a positive effect on the market for the drugs that seem to be making the whole world a little happier. We asked the HSC's Beverly Davis to shed a little light on the new drug, and she came up with a few more drugs ready to enter that market. Good times.

Although paralysis is the most obvious result of spinal cord injury, other dysfunctions occur. Loss of bladder and bowel control, erection, (erectile dysfunction) and ejaculation usually occur as well.

Almost all impotence can be treated. Among all forms of treatment, drug therapy has become the most popular. For obvious reasons, it is more appealing than injections!

Viagra is the main drug used. It is one of the most accepted drugs in recent history. Recently other new “E.D.” drugs called Cialis, Uprima and Levitra have been announced. These drugs are unique because they only work when a man is sexually stimulated. A doctor must prescribe these medications. Certain over-the-counter drugs can cause unpleasant reactions.

Uprima is only available in Europe. Levitra is not available in Canada yet. Cialis will be available in Canada within the next few months. One of Levitra's main claims to fame is that it is supposed to work faster than Viagra. The idea being that the faster acting drug allows for more spontaneity. Uprima is taken under the tongue. It dissolves immediately and is detectable in the blood in 10 minutes.

Conventional wisdom says that Viagra takes 30 minutes to an hour to “kick in”. However, Pfizer released a study in December 2002 that showed that “results showed that within 14 minutes of taking Viagra, 35% of men achieved at least one erection that resulted in successful sexual intercourse. A majority of men (51%) achieved this response within 20 minutes.” So, for many men Viagra can work in less than 30 minutes. Neither of the 4 drugs are aphrodisiacs: they will not make a man or woman want sex. They only help to

get an erection when men are sexually stimulated.

For more information about *Levitra*, please visit www.levitra.com

Bev Davis is the outpatient nurse in the Rehabilitation Hospital at the Health Sciences Centre's spinal cord injury clinic. She also teaches an inpatient group about sexuality after injury.

Noninvasive sexual stimulators

Drug	Response time	Side effects	Erection time	Contraindications	Company	Dosage
Viagra (sildenafil)	1 hour	Headaches Facial flushing Altered, bluish vision	Up to 10 hrs	Severe heart or liver problems Recent stroke, heart attack or low blood pressure Bleeding disorders or stomach ulcers Retinitis pigmentosa	Pfizer	25 mg tabs start with 50 mg
Levitra (vardenafil)	15 mins, most is 25 mins	Headache Facial flushing Stuffy or runny nose	5-6 hrs	Anyone taking nitrate drugs High blood pressure Prostrate problems	Bayer	Available in 5mg, 10mg, & 20 mg tabs. Start with 5 mg
Cialis (tadalafil)	Less than 30 mins	Headache Upset stomach Heartburn Back pain	Up to 36 hrs	As above	Eli Lilly & Icos Inc	20 mg tabs
Uprima (Apomorphine hydrochloride)	10 to 20 mins	Nausea Headache Dizziness	Up to 36 hrs	As above	Abbot	2 mg tabs



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Pushing for Rigid Frame Wheelchairs

by Ed Giesbrecht

Rigid frame wheelchairs have a solid frame that is welded at each joint. Folding wheelchairs have a flexible joint in the frame (mid-way between the wheels) which allows the chair to – as the name implies – fold up (for storage and portability). Rigid wheelchairs can be “collapsed” by folding down the backrest and removing the wheels, but the frame remains intact (in a rectangular “box”). The main advantage of a rigid frame chair lies in its “inflexibility”. With a folding chair, *some* of the effort from each “push” on the wheels is lost through “flexing” and movement in the frame. With a rigid frame, *most* of the effort goes directly into moving the wheelchair. This makes the chair more efficient, and requires less effort over time for the user.

Many individuals with tetraplegia, or other disabilities that involve four limbs, qualify for a rigid frame wheelchair through SMD Wheelchair Services. The efficiency of effort and long-term benefits are important for basic mobility and function. Many other members of CPA would also like to explore the short and long term benefits of using a rigid frame wheelchair, even though they do not currently qualify under the SMD Program. CPA has been actively advo-



cating for this option, and has had promising discussions with Wheelchair Services over the past year. Insufficient funding is the primary roadblock to SMD pursuing this avenue.

In meeting with SMD, CPA has developed a proposal that would allow users who did not qualify for a rigid chair (i.e. members with paraplegia) to pay an up-charge and receive a rigid, rather than folding, wheelchair. SMD has considered this favorably as a “pilot project”, to determine what the long-term implications and costs might be for such an alternative. In order to introduce this pilot project (on a one-year trial basis), SMD would require support from the WRHA. SMD is currently in discussion with the WRHA and is advocating on behalf of this proposal. We are hoping that support will be provided to SMD, and that we can move forward with this project. CPA will continue to keep its members abreast of this issue.

Ed Giesbrecht, OTM, is an Instructor in the Department of Occupational Therapy at the School of Medical Rehabilitation, University of Manitoba. He also is a member of the CPA Board of Directors.

Axle Grease

by Ken Davis

So, overall it was a good summer: dozens of plus-30 days, innumerable cases of West Nile, no rain for weeks on end, thousands die in European heat wave, forest fires galore globally...hey wait, it was a lousy summer!...If I read or hear one more thing about the 'iBot - The chair nobody can afford,' I'll puke....On September 4, Keegan Reilly of the USA became the first paraplegic to "climb" Mt. Fuji. The 22 year-old used a hand powered bike to accomplish the feat, along with eight assistants.....I'm still amazed at how many people don't consult the 'Shop and Swap' section on CPA's national website when they are looking for a disability related item to purchase. I bought my van off the site three years ago, and recently sold some Q-Straints....It seems that a six year old

disabled girl in Saskatoon was hoping to have an accessible playground to play in with her friends. So local mothers started fund-raising, and two years and \$200,000 later, the girl's wish came true. The park opened September 7 of this year....Research is ongoing in Switzerland and Spain on a power wheelchair that can be steered by the human mind. I actually know a few people that could sit in that chair for years and never budge it....Did you know that Canada has an annual disability film festival? The next one is being held in Calgary, from February 10-13, 2004, and the website is www.picturethisfestival.orgA 36 year-old woman in West Virginia was asked to leave the dance floor of her local bar, by the manager. His reasoning was that, "drunk people could trip

over her wheelchair and get hurt." A few days later she went back to watch her favourite band, and once again she was asked to leave the dance floor. She promptly asked for her money back, saying that if she couldn't dance she shouldn't have to pay. The bar gave her the money back, then kicked her out, saying she "couldn't watch the band for free."....Next time someone tells you to get a job, as my wife does daily, just log on to www.workink.workopolis.com. The site bills itself as the 'premier site for job seekers with disabilities. The site is proudly brought to you by workopolis.com and CCRW (Canadian Council on Rehabilitation and Work....Hope everyone has a great Halloween, Hanukkah, Christmas, Kwanza, New Year's Eve and Groundhog Day.



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).

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

For Sale – EJ Metro Plus Wheelchair – 22" wheels, 16" seat, well padded. Paid over \$1000 – used one month. Asking \$500.00 – Call 832-5100.

For Sale – '88 Dodge Van Ram 250 V8 with raised roof and Ricon Elec. W/C lift installed by Custom Coach Works Dec. 98. Good body, good tires, good runner. Asking \$7000.00 Call 772-2313

For Sale – Tracer Wheelchair – well padded, does not fold. Paid over \$1000 – used three months. Call 832-5100.

For Sale – Wheelchair Lift - Braun Fully Automatic Lift-A-Way Series 03. Both remote control and interior control. Can be operated by occupant. Includes wheelchair tie-downs (no anchors). Used less than one year. \$3,000. Contact Frances at (204) 946-7155 or frances.harris@gwl.ca

For Sale – Electric Medi-Lift Recliner. User can go from full recline to full standing position. Rose colour, excellent condition. Asking \$750.00. Call 885-1135.

For Sale – Pace Saver Plus 2 Excel 3 Wheel Scooter - \$1000 OBO. Call Dennis at 224-2715.

For Sale – Janson 3-wheel hand pedaled tricycle. 3 speed, leg rests, good for recreation and exercise. Legs rest in forward position, rider not in sitting position. New tires. Call Derek at 837-1290 (evenings) or 945-5815 (days). \$550.00 for CPA members.

For Sale – Roho dry floatation cushion for 20 x 18 chair size. Excellent condition. Asking \$250.00. Call 772-2313.

For Sale – Invacare Action Arrow Storm (1994) power chair - Black with purple vein color - front & back shock suspension (set of larger casters - no suspension) - new batteries & tires - gear motors 1.5 years old - will require seating customization. Asking \$2000 - For more info Call James at 949-1150.