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Research Realities

SCIENCE IS A SLOW AND TRICKY BUSINESS. It creates a lot of hope. But it also creates a lot of hype that too often exceeds realistic hope.

During my first week as a PhD student, my supervisor appeared in a national television news story about some interesting advancements in the understanding of SCI and regeneration. When asked when there might be a cure, he responded that there could be one in five to ten years. "Wow!" I thought. "Did I ever pick the right time to join this lab and the field of SCI regeneration research."

That was almost exactly 20 years ago.

There is still no breakthrough or treatment out there that will repair or regenerate the spinal cord and totally cure SCI. Science and medicine do not have the tools to reverse SCI and allow those who do not have enough spared tissue to walk again. They do not have the tools to eliminate chronic pain, to completely repair bowel and bladder function, or to fully restore sensation (sexual and other). Maybe someday—but not today, and likely, not tomorrow.

That's not to say there hasn't been progress. There has been plenty. Some of it is making a difference in the lives of people with SCI every day. Think of the advancements in rehabilitation to maximize potential and in assistive technologies that allow for more inclusion and participation, be it in the workplace, at home or in recreational and leisure pursuits.

But it's important to separate the reality from the hype.

The focus of the hype shifts as science makes new discoveries. Lately, the hype has been dominated by stem cells, seemingly the answer to everything. Unlike many other discoveries over the past two decades, stem cells have maintained the hype longer than others. I think back to 10 years ago, when I had finished my PhD in SCI research and had become Managing Director of ICORD, the world's largest SCI research centre. One of the first things I was asked to do was to present a frank and honest account of the state of SCI research at BCPA's Annual SCI Forum. The forum committee, comprised of BCPA and GF Strong staff members, asked me to balance the hype-filled hope being generated by research with the realities of the state of current research. Why? Because, I was told, people with SCI believed a cure (particularly involving stem cells) was just around the corner. As a result, they weren't bothering to do rehab or to find ways to maximize their potential and learn to get the most out of their lives. They were in a holding pattern waiting for the cure.

Time has proven the need for cautious interpretation of scientific advancements, particularly when it comes to a cure for SCI. The research community is incredibly passionate and continues to make important advancements in all aspects of SCI—some that will make a difference today, and some that are small steps toward treatments in the future.



Chris McBride
Executive Director, BCPA



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Last year, Miami-based Vehicle Production Group unveiled the MV-1, the first vehicle designed and built from the ground up specifically for wheelchair users. In other words, it's the first vehicle of its kind that doesn't require extensive modifications (often involving cutting and re-welding of the frame) to safely accommodate passengers or drivers who use wheelchairs. It features a built-in ramp and extra headroom for easy entry and exit. The MV-1 uses a traditional body-on-frame design, with a Ford 4.6-liter V8 engine and rear wheel drive, similar to the Crown Victoria. So far, there are 50 dealerships across the US; many already have a waiting list from interested consumers, and at least two taxi companies have placed significant orders. Here in Canada, it will be distributed by the Motion Group of Companies. A company spokesman told us that Motion Group has been working with Transport Canada since July 2011 and expected compliance and launch of its dealer and service network in February. Visit www.motiongroup.ca for more information.

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Sailing Ahead.

The Disabled Sailing Association of BC is offering a series of get-togethers in preparation for the upcoming sailing season. Plan on attending whether you're a skilled sailor or interested in trying this fun and addictive adaptive sport for the first time. The events will be held at GF Strong Rehab Centre's Social Services Seminar Room from 6:30 PM to 8 PM on the following dates: March 22, April 26, and May 17. This year's sailing season gets underway on May 30 and runs through Friday, August 31. More info can be found at www.disabledsailingbc.org.



Walk 'N' Roll.

This year, for the first time, the Vancouver Scotiabank Half Marathon's 5K race has been classed as accessible for people with physical disabilities. BCPA will enter a team consisting of people with SCI and their able-bodied friends and family members. Join us in our quest to raise \$25,000 to help fund our crucial services to British Columbians with SCI or related physical disability. To sign up as a "Walk 'N' Roller" visit www.bcpa.org or www.canadarunningseries.com. Questions? Contact Gary Steeves, gsteeves@bcpa.org or 604.326.1210.



Rick Hansen Celebration.

Rick Hansen Celebration 25 takes place on May 22, 2012, 25 years to the day after the conclusion of the Man In Motion World Tour. The event, which will signal the end of the Rick Hansen 25th Anniversary celebrations, will honour remarkable Canadians, recognize everyday heroes and feature performances by well-known Canadian recording artists, including Sarah McLachlan, Jann Arden, David Foster, and Marianas Trench. The event takes place at 7:30 PM at Vancouver's Pacific Coliseum. For more details, see www.rickhansen.com/celebration25.

Under One Roof

The BC Paraplegic Association (BCPA), BC Wheelchair Basketball Society (BCWBS), BC Wheelchair Sports Association (BCWSA), and Disabled Skiers Association of BC (DSABC) are moving in together. As of March 1, each of these organizations will be headquartered under the one roof on Marine Drive in Vancouver, the same building where BCPA has resided for the past 36 years.

"The move is an exciting step for all of our organizations which, despite providing very different services, are all working towards the same goal – improving the quality of life for people with spinal cord injuries or related disabilities," says BCPA Executive Director Chris McBride. "It's going to be great having the four organizations united under the one roof. This will enable us to share information, resources, and work together more effectively."

Kathy Newman, Executive Director of BCWSA also shares McBride's excitement. "BC Wheelchair Sports was born in the BCPA offices in 1971, and we are excited to return to our roots 40 years later," she says. "We're excited to be working alongside BCPA to continue to deliver exceptional services to people with disabilities."

Update: Neuropathic Pain

In the March 2011 issue of *The Spin*, we told you about Dr. Min Zhuo, the University of Toronto professor of physiology who had made some promising discoveries in eliminating neuropathic pain with a compound known as NB001. You'll recall that Zhuo's approach involved eliminating neuropathic pain in the brain as opposed to the traditional approach of eliminating it at the site of the offending nerve.

Several readers have prompted us for updates on this story. Unfortunately, Zhuo reports only limited progress in finding partners and funding for a human clinical translation of his approach. "We are still working with a few companies to reach potential joint agreement," says Zhuo. "Due to economy fallout everywhere, many major companies are even pulling out pain drug markets altogether. This is why we often call it 'lost in translation.' I do feel bad for such slow progress in pushing for clinical tests, considering so many patients are wanting to try better pain drugs."

Zhuo says he remains committed to his research and testing NB001 in human trials. We'll provide updates on his work as they become available.

Skating in his Blood

Almost a decade after his injury, Chris Somerville remained so passionate about skateboarding that he made it his business.



“Skateboarding,” says 32 year-old Chris Somerville, “is all I know.”

And that explains why, last August, Somerville opened Street Dreamz—a board shop in North Delta that caters to the youth and young adults in the Surrey/North Delta community. In less than a year, Street Dreamz has become a thriving business and a big part of the lower mainland’s thriving skateboard scene.

Street Dreamz offers the latest in cutting edge products and trends, along with different services like re-gripping, repair, and assembly of skateboards and longboards. In his well-stocked shop on Scott Road, customers will find a selection of more than 200 skateboards to choose from, along with parts, accessories, and clothing—all with some of the best prices in the business.

“Our focus is to provide top-of-the-line apparel, shoes, boards, and accessories in a relaxed environment,” explains Somerville. “Some customers even refer to us as their ‘home away from home’. We carry a wide selection for any skateboarder, whether you’re a beginner just starting out, or a pro who’s been skating his whole life.”

While Somerville is basking in the glow of success, make no mistake: it’s been hard-won over the course of a nine-year post-injury grind.

At the age of 23, he was a sponsored skateboarder near the top of his sport. On the night of July 23, 2003, after spending the day perfecting some tricks for the upcoming Slam City Jam, he and some friends caught a ride home—Somerville didn’t know the driver, but one of his friends vouched for him. Along the way, the driver cut a corner too close and went over the curb. Officers in a passing police car saw the incident, but

when they attempted to stop the car, the driver – who turned out to be just 14 years old – panicked, sped off and ultimately crashed.

The next thing Somerville remembers is waking up in hospital. He was the only one injured in the crash, and in the blink of an eye, he’d become a T11-T12 paraplegic.

“I remember when the doctors told me I was paralyzed and that I would never walk again,” he says. “At first, it was pretty





Left: Chris Somerville at work in his board shop. Centre: English Bulldogs Buster and Aveo, the shop's two unofficial mascots, garner a lot of attention, even from people who would typically never enter a skateboard shop. Right: Somerville still spends time at local skateboard parks, where he enjoys mentoring young skaters and creating videos of their routines.

hard to deal with. I was depressed. But I was determined to get better.”

The same tenacity that had made Somerville a great street skater also allowed him to persevere during his recovery. After three months in hospital, he moved to GF Strong, where he continued rehab, mastering brace walking along the way.

Three months later, he was discharged. In 2004, he used a portion of his modest settlement to purchase a hand control-equipped car, and he moved into an apartment in Vancouver. At that point, he realized he needed to get a career going. He enrolled in Vancouver Community College, where he took

graphic design and writing courses.

Despite acquiring new skills, he struggled to find any kind of meaningful employment.

In 2008, he moved out to Delta to be closer to his girlfriend, Gillian (now his fiancée). Frustrated with his lack of success finding work, and with his love for skating always at the back of his mind, he began researching business opportunities. And that’s when he discovered the Surrey-based SEEDS (Self-Employment and Entrepreneur Development Society) program, which offers training and some financial help for entrepreneurs with disabilities.

“I really wanted to re-enter the workforce and become a contributing member of society again,” says Somerville. “I completed the program successfully and fulfilled one of my lifelong dreams—opening my own skate shop.”

Along the way, Somerville learned a great deal about himself and the realities of business.

“From planning out, to building, opening and now running the business, I’ve learned it’s very hard and challenging,” he says. “And to keep the ball rolling, you have to work twice as hard. But on the flipside, it’s awesome—I enjoy every aspect of it, especially talking to the customers about the newest products and taking the time to see what exactly they need, and just listening to the local kids who come in to share the day’s adventures.”

In particular, Somerville has discovered effective marketing is equally important as great customer service and product selection. Needless to say, the writing and graphic design skills he learned in college have been put to good use, on his website and in other online spaces.

“Our marketing strategy,” he explains, “focuses heavily on social media. We use platforms like Facebook, Blogger, YouTube, and Twitter. Social media technology has provided scale and has enabled Street Dreamz to reach a global audience.



These technologies allow us to network with other skateboarders in our own and other communities. It also gives us the advantage to see what our competitors are providing on a daily basis."

Community involvement, he adds, is another aspect of his marketing strategy—and something that gives him a great deal of personal satisfaction. "This year we plan on hosting some competitions and team demos at local skate parks. We're currently working on our first shop video featuring our talented team of shop riders. We also plan on helping our community skateboarders get approval from the City to get outdoor lights installed in the Delta Rotary Skate Park. We want to grow along with the youth and families in the community and establish ourselves as a permanent fixture here. So far, the community response has been very supportive and overwhelming."

He also says that having an SCI gives him a competitive advantage. "The unique aspect of owning a skateshop

and supporting an industry that would typically not be associated with someone with an SCI opens a lot of doors for conversation and grabs people's attention," he says. "If I have a some spare time or a day off, you can find me hanging out with my brother and friends at the skate park. I get a huge reaction from the kids at the skate parks; most eyes are watching and minds are wondering, 'What exactly am I doing here?' Usually I'm filming others skateboarding or sometimes I like to drop into the park itself and roll around. It's then when I get a huge response from people, and I guess at that point, some just think I'm crazy."

As for personal goals, Somerville has linked up with the Rick Hansen Foundation and is eager to share his story in local schools. "I'd like to bring awareness to youth about achieving your 'Dreamz' no matter what your limitations may be, and close the gap on discrimination and lack of understanding about SCI. I've also been asked to partake in the Rick

Hansen 25th Anniversary Relay in May 16th from Abbotsford to Maple Ridge, which is a great honour for me."

But he won't stray too far from his fledgling business.

"My love for the sport is my entrepreneurial strength and why I desire to be self-employed," he says. "For me, as someone who was a skateboarder—and still is at heart—and as someone who has an SCI, owning a business like this is a perfect fit. It's a job I can physically do. It's a job I want to do. And because of that, I love it.

"My advice to anyone planning on starting their own business is to figure out what it is that you enjoy doing, or have enjoyed doing, and make it your own. Always follow your passion and to never let go of your 'Dreamz'." ■

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Risky Business

When it comes to stem cell therapies, hype is overshadowing hope—and people with SCI are gambling with their health and money. ■ By Dr. Chris McBride, BCPA Executive Director

Last July, BCPA staff were stunned to see a TV news story from A Channel (now CTV Vancouver Island) that all but promised viewers that the cure for SCI was just an airplane ticket away.

"The use of stem cells for medical treatment may be a legal and ethical minefield, but there is no question the procedure works—at least there is no question from the people who have benefitted from it," gushed the newscast's anchor. "Canadians are travelling to India and China for stem cell injections and they are showing incredible improvement...Meribeth Burton begins a series of reports tonight on stem cells and the difference they're making for people who are living with spinal cord injury."

BCPA has always avoided moralizing or sermonizing to our peers and members. But we are in the business of supporting and empowering British Columbians with SCI, and one of the most important ways we achieve this is through the provision of critical information. The steady rise of media and internet-driven hype over stem cells and the resulting increase in stem cell tourism prompted us to develop an article on the realities of this predatory industry. The news story on A Channel highlighted exactly why we needed to do so.

We understand the willingness of many people with SCI, especially in the early years after injury, to risk their health and money in pursuit of what they hope is a cure. However, the stark reality is that there are no treatments available today that represent a cure. Nor is there any current research that will lead to a cure in the near term.

This is not to say that research is not making progress. It is. Many advancements in rehabilitation, reducing secondary health complications, assistive technologies, and other aspects of health and quality of life are having positive impacts today. But when it comes to a cure, we're a long way from the goal. SCI is incredibly complex. While researchers worldwide are gaining a better understanding, they will need a great deal more time.

With this in mind, we hope this article tempers the hype that has been generated over the current state of stem cell therapies.

We believe that no person who is fully informed would ever make the choice to travel to a developing country for an expensive, potentially dangerous, and entirely unproven procedure.

When hope is twisted into hype

Like many organizations and stakeholders in the world of SCI, BCPA believes in the potential of stem cells as a component of a future treatment for SCI. We base our cautious optimism on early-stage progress in research involving animal studies, and on the fact that stem cells therapies are being successfully used in at least one human disease (e.g., bone marrow transplants for cancer patients).

But let's be clear: there has never been a scientifically credible success involving human SCI and restoration of function after stem cell treatments. The closest we've come was the FDA-approved phase one clinical trial in the USA led by Geron, a pioneer in stem cell research. It involved five people with paraplegia who, shortly after they were injured, received transplants of human embryonic stem cell-based product. Late last year, the study appeared to be on its way to achieving its goal of demonstrating safety—so far, none of the candidates have had any adverse effects. But after investing 15 years and \$150 million, Geron shut the trial down shortly after. This was a huge disappointment to the global SCI research community and people with SCI alike. The reason, according to the company, was insufficient funds, but the seemingly low potential of their therapy for functional improvements to be realised through even more expensive Phase 2 and 3 clinical trials no doubt contributed to their decision.

Of course, Geron wasn't the only player in the field. There are a small number of other scientifically credible trials underway. An Australian study of six paraplegics has also demonstrated safety (but again, no improvements) in transplants of stem cells obtained from the subjects' nasal tissue. And we're particularly looking forward to positive outcomes from a Phase I/II clinical trial led by Dr. Armin Curt at the Balgrist University Hospital in Zurich, Switzerland. This trial uses a type of stem cell derived from human brain tissue, and will seek to transplant these cells



into 12 ideal subjects over the course of five years. Again, the main goal of this phase of the study is to prove safety, and results are several years away.

So, despite claims made by clinics in various parts of the world and testimonials from some who have visited them, there is not even a shred of scientifically credible evidence that proves that, in humans, stem cells can be coaxed into replacing nerve cells damaged by SCI and restoring any kind of function. In fact, there is very little evidence yet from animal studies to suggest a stem cell cure is just around the corner.

So why is it that a Google search for “stem cells” and “spinal cord injury” yields dozens of results—websites for clinics in far-flung corners of the globe that make a range of promises from improving bladder and bowel function to providing an all-out “cure” for SCI? Second, and far more concerning, why is it that some Canadians are visiting these clinics, spending upwards of \$75,000 in the hopes of getting benefits that simply aren’t possible, and risking disease and even death in the process?

We believe the basic answer to the first question—why these clinics exist—is greed that preys upon desperate hope. These clinics don’t exist in Western world countries where we have regulatory bodies that prevent patient exploitation and quackery. Instead, they exist in unregulated countries where a virtual wild west of medicine is the norm—China, India, Russia, Panama and Ecuador are examples. With low expenses and no shortage of clients desperate enough to travel long distances and fork over their savings, the profits are just too tempting to unscrupulous clinic operators lacking any type of regulatory oversight.

Of course, these clinics wouldn’t exist without demand. This brings us to the second question: why are Canadians with SCI becoming stem cell tourists?

We have no way of knowing the exact number of people with SCI who have been abroad for stem cell therapy. But from anecdote and news stories like the one we told you about at beginning of

this article, the number appears to be substantial.

The reasons, we believe are complex.

To begin with, consider the devastating nature of SCI, for both people who sustain them and their loved ones. Here at BCPA, over half a century of experience tells us that some people with SCI, particularly those in the period immediately following their injury, are unwilling to accept a prognosis of life with paralysis. For others, excruciating pain and other secondary complications of SCI can also lead to a desperate search for a miracle cure. Hope can sometimes be unrealistic, and people can be so vulnerable and desperate that they make life-altering decisions that fly in the face of common sense, empirical evidence, and advice from their own medical team.

Second, the clinics offering stem cell therapies are highly skilled at luring “patients.” Central to their success are slickly-produced websites that sway the potential stem cell tourist—not by offering any type of credible scientific evidence of their therapies, but instead by providing what appear to be powerful testimonials, often recorded on video. These websites and the clinics behind them have more in common: they generally make unrealistic claims about safety and results, focus the reader on what appear to be impressive credentials of the clinic operators, and are vague about any details about their procedures and source of stem cells.

Third, we think it needs to be acknowledged that there’s a disconnect between people with SCI and the research community. Because of lack of information, people with SCI often become frustrated with what appears to them as a lack of progress and unwillingness by researchers in the western world to move promising animal studies more quickly into human clinical trials. Too often, that frustration morphs into misplaced action—becoming a stem cell tourist.

Finally, it’s clear that some people believe that, by becoming a stem cell tourist, they’re not only doing what’s right for themselves, they’re contribut-

ing to research and a growing body of knowledge. The reality is quite different. Although there are now a miniscule number of legitimate clinical trials involving stem cells and SCI, they have strict criteria for being included in them and they do not charge money to be a participant—they aren’t allowed to. Clinics that are requesting payments of tens of thousands of dollars are not involved in any of these legitimate research efforts—their motivation is profit only.

So what do we suggest?

First, please understand that we’re not criticizing anyone who has travelled abroad for stem cell therapy, or anyone considering it. BCPA is an organization that walks the walk (or wheels it, if you prefer). People with SCI created BCPA more than five decades ago, and have always helped to guide our organization—as members of our board, as volunteers in other capacities, and as employees in critical roles. Based on our combined personal and professional experiences, we understand how powerful the desire is to walk again, or be rid of neuropathic pain and other secondary complications, particularly in the first few years after injury.

Instead of criticizing, what we’re doing is asking our readers to carefully weigh hype versus realistic hope, and to base your own positions and decisions on stem cell research and stem cell tourism on fact and honest self-assessment. Here’s what we suggest.

Learn about stem cells and stem cell research. Yes, the science is complex. But the basic principles are within our grasp. It’s important to understand what these cells are and what they’re not. It’s also important to understand what the hurdles are as we seek to understand how they can play a role in SCI. For example, we need to better understand the best type of stem cells to use in SCI, how they can be obtained, and when and how to deliver them to the right part of the spinal cord. We also need to understand how these cells can be “programmed” to replace and/or repair damaged cells in the spinal cord. The truth is that we don’t

Stem Cell Tourism: Notable Quotes

"Stem cells have the potential to turn into any kind of cell and, in theory, they could repair damaged cells though scientists tell us that we're years away from realizing that dream. There is no stem cell miracle today, so comen have moved in to offer the hope that science cannot." – CBS correspondent Scott Pelley, *"Stem Cell Fraud"*, 60 Minutes, January 12, 2012

"I understand several persons with SCI are spending vast sums on stem cell treatment in the hope of improvement. This is a sad state of affairs. Persons with SCI must not go in for treatment using stem cell or olfactory ensheathing cells in any part of the world, as there is a long way to go to have a scientifically proven approach that also works. The money that is or could be spent on stem cell treatment must be used to improve the quality of life in other ways and not wasted in this treatment now." – Professor Alan Mackay-Sim, *Director of Australia's National Centre for Adult Stem Cell Research*, The Hindu, January 12, 2012

"International scientific organizations, patient advocacy groups, and, in a few notable cases, national governments have roundly condemned these therapies...But despite such action, the industry continues to flourish, generating false hope, robbing families of their resources, and potentially compromising legitimate stem cell science." – Dr. Timothy Caulfield, *Research Director of the Health Law Institute at the University of Alberta*, "Blinded by Science", The Walrus, September 2011

"People with SCI, as with any serious medical conditions, are highly susceptible to advertisements promising recovery, even when the costs are high and potential risks are unknown. It is morally unacceptable to prey on and profit from their hope for a cure. We believe that it is unethical to charge these patients for experimental

interventions that are not yet proven safe and effective by properly conducted clinical trials." – *The International Campaign for Cures of Spinal Cord Injury Paralysis*, "Position Statement on the Sale of Unproven Cellular Therapies for Spinal Cord Injury"

"I tell them that whatever function they currently have, they would jeopardize, and they would take on the risk of suffering complications from the procedure such as nerve pain, infection, neurologic worsening, or even cancer. All this for something that is quite likely to not work, despite the testimonials from patients. I also tell them that many patients feel like they've improved even though objectively there is no difference. I also point out that most patient testimonials are from people very soon after their procedure, when they feel like any little difference is 'improvement'; these typically do not persist as long term benefits, however, and people realize that they are not really much different down the road." – Dr. Brian Kwon, *Vancouver Coastal Health spine surgeon and ICORD scientist*, when asked how he responds to patients inquiring about stem cell therapies

"A young paraplegic man desperate to find a cure died following a controversial stem cell operation in Ecuador, an inquest heard... (Ricky Chick) decided to travel to Hospital San Francisco in Guayaquil, Ecuador for private treatment using stem cell technology...when Mr Chick came round, he could not stand any noise and wanted to remain in darkness...The former body builder died the following day, the inquest heard. Coroner Doctor Roy Palmer said: 'Intracranial hypertension had caused Mr Chick to cardiac arrest. His death was a result of treatment that didn't work out.' Pathologist Dr Olaf Biedrzycki told the court the operation had caused brain swelling." – James Pepper, *"Croydon man died in long haul op, inquest hears"*, Croydon Guardian, January 26, 2011

really have the answers to any of these questions. We're confident that, once you learn about the basics of stem cell research, you'll be able to better accept that research in this field is in its infancy, incredibly expensive, and that it requires a great deal of time.

Learn about the risks—and lack of rewards—of stem cell tourism. Accept the lack of real evidence for any stem cell therapy you see advertised online. It just doesn't exist. Flashy websites and compelling testimonials are not replacements for solid evidence. Meanwhile, recognize that surgery has the risk of adverse effects and learn about the deaths and injuries associated with questionable stem cell therapies offered abroad. And given all this, ask yourself how you could improve your life by saving the tens of thousands of dollars you'll need to be a stem cell tourist—or using them to buy better mobility aids, rehab or exercise equipment, or assistive technology.

Understand and accept human

behaviour. The temptation to chase an elusive cure in the face of all rationality lies within all of us, particularly in the period immediately following the onset of a life-altering disability such as SCI.

In the same vein, we are all highly suggestible to the power of testimonial—the kind that we see on the websites of offshore stem cell clinics and in human interest stories in the mainstream media. Studies have demonstrated that we are all more likely to be swayed by a powerful testimonial than cold, hard facts.

That brings up an important question: why do people provide these testimonials? First, let's discard the blatantly fraudulent—the kind in which someone claims they've regained the ability to walk or have been cured entirely. That leaves the many testimonials that we can read online everyday in which the subject claims better hand function, more sensation, an improved bowel or bladder function, and so on. Is it possible that people have actually experienced these

things? Yes—but the lack of scientific evidence almost certainly means that these improvements are either improvements that would have occurred in the recovery process that often continues years after injury, or as the result of the aggressive exercise and therapy programs that are almost always prescribed as part of the stem cell transplantation process. There is also the very powerful placebo effect, the research-proven phenomenon by which someone can feel better after being given a treatment that, unbeknownst to them, was a sham.

When you recognize and accept these aspects of humanity, you'll be able to better understand your own decision-making process and learn to make decisions that are based on fact and reality.

Accept that scepticism is good. Scepticism is often mislabelled as pessimism and seen by some as something negative. It's not—scepticism lies at the heart of all scientific discovery and underpins most medical breakthroughs. Only

through questioning all aspects of a theory can we move forward on a basis of fact.

Learn about the power of peer support. If you're thinking about stem cell therapy as a last hope for a meaningful life, consider reaching out to peers who have lived with SCI for years or decades—people who may have been tempted by similar promises of miracle cures (as most have at some point) but instead have, over their years of experience, increasingly embraced a balanced approach of acceptance of their injury and enjoyment of life, along with a realistic hope for research advances. BCPA can help you connect with peers—visit www.bcpa.org for more information.

Progress is being made

On the face of it, stem cell tourism appears rampant, but progress is being made to protect consumers.

There is a growing recognition by some governments that failing to shut down illegitimate clinics is actually doing damage to their international reputations and compromising their own legitimate research efforts. For example, in January, China's Ministry of Health announced that the country has stopped all unproven and experimental stem cell treatment programs.

On another front, responsible members of the media are helping to shed light on the pitfalls of stem cell tourism. On January 12th, the CBS show *60 Minutes* pulled no punches when exposing one such clinic and its operator, Dr. Dan Eklund (see "Notable Quotes on the previous page). A similar *60 Minutes* expose aired two years earlier also led to a federal probe and charges being laid against two Texas men in January.

We're also heartened to see conscientious and concerned researchers and other stakeholders collaborate in order to better educate the public. Notable among these is the International Society for Stem Cell Research (ISSCR), an independent, non-profit organization formed in 2002 to foster the exchange of information on stem cell research. With more than 3,500 members world-

wide, ISSCR appears to have become the de facto voice of the stem cell research community. This organization's website (www.isscr.org) contains a wealth of information. Also notable is Canada's Stem Cell Network, which seeks to enhance collaboration between Canadian researchers and reach out to the public with up-to-date information about stem cells (www.stemcellnetwork.ca). There's also a growing number of concerned individuals committed to becoming sceptical watchdogs—for example, check out www.sctmonitor.blogspot.com.

Another real advance is education of family physicians, who are often unsure of how to counsel a patient who expresses interest in stem cell tourism. The Spring issue of *Canadian Family Physician* contains a straightforward set of bullet points for doctors to communicate to patients. This resource was developed by the Toronto Stem Cell Working Group led by Dr. Timothy Caulfield, research director at the Health Law Institute at the University of Alberta. Similarly, the International Campaign for Cures of spinal cord injury Paralysis (ICCP) has a checklist of things individuals should consider before deciding whether to participate in a stem cell trial (<http://icord.org/documents/iccp-clinical-trials-information>).

Keep the hope. Reject the hype.

Here at BCPA, we've never given up the hope for research successes that lead to restoration of function after SCI. We're also hopeful that stem cells may some day prove to be part of the answer. But it's important to remember that limited success in animals does not mean human success is just around the corner.

Hope is a powerful and productive emotion, but it must not arise from misdirected hype. When it comes to stems cells and a cure, hope is for something in the distant future. In the meantime, join the thousands of British Columbians with SCI who have rejected hype and found other ways to make the most out of life. ■

To participate in a quick poll on stem cell tourism, visit www.bcpa.org.

Underwater

In the last issue of *The Spin*, we told you about a research study that suggests there are some therapeutic benefits from scuba for people with SCI. The jury might still be out on that, but there's no doubt that scuba is an exhilarating experience for anyone, including people with SCI.

Recently, Rob Roseberry, our Kelowna Peer Program Coordinator, along with instructor Jen Craig-Evans of Kelowna's Diving Dynamics, organized a "Discover Scuba Diving" event for our Okanagan peers. Along with Roseberry, three peers took the plunge—Daniel Schermeto, Mark Peeren, and Anand Peeren (that's Anand in the photo below).

The pool-based, non-certification program incorporated a safety briefing, instruction of a basic skill set, and the wonderful experience of those first breaths underwater in a weightless environment.

"I'm very pleased to report that this event was a success, and we had great feedback from those who participated," says Craig-Evans. "Going forward, we'll build more familiarity and confidence in the water, working towards developing all skills necessary for certification. This would ideally involve all academic and pool work here in Kelowna, and the open water portion somewhere tropical."

Watch for details in future issues.



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Power Platforms

Front, mid or rear wheel drive: which one is right for you?

Are you in the market for a new power chair?

You have many choices. But perhaps the most important decision to make as a starting point is what kind of drive system is best for you—front wheel drive (FWD), mid wheel drive (MWD), or rear wheel drive (RWD).

Rehab & Community Care Medicine, Canada's quarterly magazine for rehabilitation professionals, offered an excellent comparison of the three drive platforms in their Summer 2011 issue. The author, Allan Boyd, points out there is little scientific research on the subject. As a result, the comparison is based on the experiences of "individuals knowledgeable in the real-world performance of these platforms."

The comparison was made in six categories: indoor performance, outdoor performance, smoothness of ride, stability, driver and seat positioning, and intangibles such as intuitive feel. Here's a quick summary of how each of the platforms scored.

INDOOR PERFORMANCE. The main goal in this area was to determine which of the platforms is the most maneuverable in confined spaces. MWD was a narrow winner over FWD in this category, mainly because it has about half the turning circumference as the other two platforms.

Surprisingly, FWD will actually negotiate a tighter turn than MWD, but if you need to rotate completely in a tight space, MWD is far better.

OUTDOOR PERFORMANCE. The goal in this area was to find the platform that could best get you to your destination over less than ideal terrain. Factors that contribute to better outdoor performance include size of drive wheels, width of drive footprint, ground clearance, power and torque, and sensitivity to weight distribution. FWD was the clear winner: its large front wheels get over obstacles easier; it has the best traction, it pulls rather than pushes castors (better when it comes to negotiating obstacles and soft terrain), and it doesn't "high centre" as the other platforms tend to,

SMOOTHNESS OF RIDE. The goal in this category was to determine which platform reduces rocking and bouncing for the user traversing less than ideal surfaces. Because FWD and RWD platforms can incorporate independent suspension, they are clear winners over MWD, which has four casters (for a total of six wheels) instead of two.

STABILITY. This is an important consideration when a tilt or recline power seating system is needed. FWD gets a slight nod over MWD here, with RWD far from ideal. "In

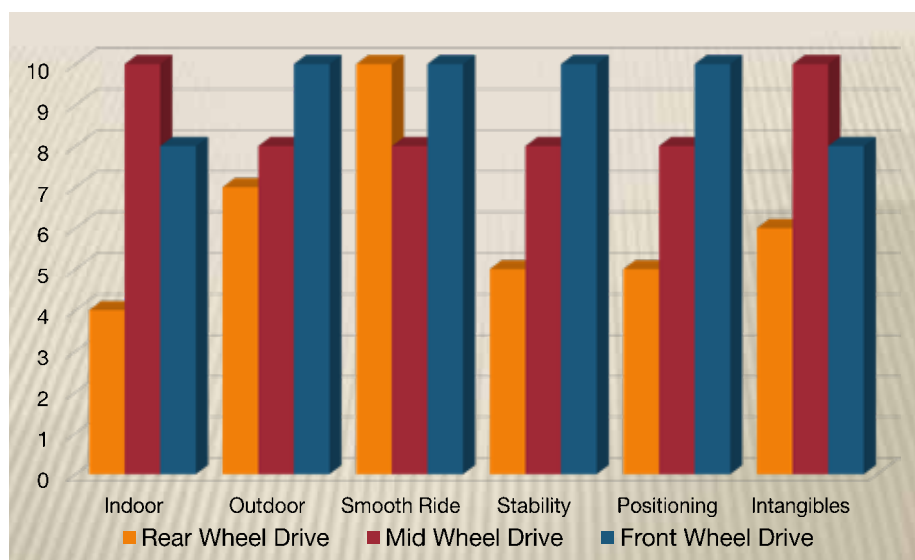
my experience, MWD and FWD are generally preferred over RWD when stability is considered,” writes the author. “This is because their architecture provides more options for the ideal positioning of the driver and location of the powered seating system.”

DRIVER AND SEAT POSITIONING.

The goal in this category is to determine the platforms which least compromise user stability by avoiding positioning power seats too far forward in order to maintain appropriate leg and foot space. With no front casters, FWD edges out MWD in this department. RWD does not score well in this area.

INTANGIBLES. This area relates to the users’ “intuitive feel” about the various platforms. In other words, some platforms feel more intuitive to drive and control. Having the turning pivot point close to the user’s head, as well as the ability to access tight spaces, contribute to a better feel. MWD is the best performer in this area, followed closely by FWD.

Obviously, there are many more factors than drive system to take into account



when you purchase a new power ride. The amount you can afford, the amount of insurance coverage you have, and various seating options and needs available for each manufacturer’s models are among these. But using the information above and balancing it against your own personal needs, desires and budget will allow you to make an educated decision about the most appropriate drive system

to choose as a starting point.

As always, a qualified occupational therapist or seating specialist can help you make the final decision.

If you need help to determine if you qualify for the various funding options, or if you need advice on how to enlist the assistance of a seating specialist, please call our knowledgeable experts at the BCPA InfoLine—1.800.689.2477. ■

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North to Alaska

Got the travel bug? An Alaskan Cruise is a good mix of port and sea days, you're never far from home, and you can board practically right in your own back yard. ■ By Amy Billingsley

As our BC weather starts to turn from really wet to slightly less wet, I get asked more and more about cruising to Alaska—and with good reason. An Alaskan cruise offers a truly unique opportunity to get up close and personal with magnificent glaciers, observe wildlife in its natural habitat, take a scenic train ride or even pan for gold. You can experience all of this using some of the world's most luxurious cruise ships as your home-away-from-home, several of which sail roundtrip from and back to Vancouver's downtown pier.

Best of all, because cruise lines offering Alaska sailings must conform to the Americans with Disabilities Act (ADA), most excursions and activities are wheelchair accessible.

Of course, cruising makes a fantastic accessible vacation for a lot of other reasons. Because of the ADA, cruise ships offer superb accessibility onboard, in your cabin and throughout the vessel. Wide door frames, spacious bathrooms and roll-in showers, built-in shower chairs, raised toilets with stability bars, and roll-up sinks are among the accessibility features designed to make your cruise as comfortable and free of barriers as it can possibly be.

Like all passengers, you'll quickly fall in love with cruising's other perks. You only need to unpack and pack once. Every day you arrive somewhere new. And the gourmand in you will discover that dining on Alaskan cruises is fantastic, with almost all meals included in your upfront fare—unless, of course, you want to have a romantic dinner at one of the specialty restaurants onboard. After dinner, the free entertainment is always great and the

port experts are willing to give you advice on any sort of accessible activity you could wish to undertake.

Cruise ships start showing up in our port in May and commence sailing with back-to-back itineraries, either seven or 14 days, up until mid-September.

Those of you looking for a deal will find the most economical fares in May and September. Keep in mind that you're cruising to Alaska and not Aruba, so these are also the months when you're going to get the most chill in the air. If you're looking for the right balance between on-board demographics, weather and price, June is probably your best bet. Cruise lines know that, come July and August, kids are out of school and the weather is more stable. So the price can go up significantly in these months.

Another consideration is what type of stateroom you'd like to cruise in. I typically suggest an ocean view since it offers you sunlight and scenery at a good price. But keep in mind that the closer to the season we get, the scarcer accessible ocean view rooms become. If you feel like spoiling yourself, a balcony or suite is a great way to go too. Nothing beats scenic cruising while enjoying room service on your private balcony.

Each cruise line offers a slightly varied itinerary, but only two sail round trip from Vancouver on a weekly basis: Holland America, which offers cruises on the ms Volendam and the ms Zuiderdam; and Celebrity, which is offering the Century.

Holland America's ports of call are Tracy Arm (scenic cruising), Juneau, Skagway, Glacier Bay (scenic cruising),

and Ketchikan. The Celebrity's ports of call are Icy Strait, Hubbard Glacier (scenic cruising), Juneau, and Ketchikan.

These ports offer a wide variety of accessible excursions including accessible wildlife cruises, panning for gold, meeting a sled dog team, and hopping on the White Pass & Yukon train. But if you want to just sit back with a mug of hot chocolate, that's OK too.

You can also extend your stay. Celebrity and Princess offer northbound and southbound itineraries that include a three-day add-on in one of their Denali lodges. These lodges offer all of the modern amenities but are nestled in the heart of the wilderness and offer breathtaking mountain views that shouldn't be missed. You'll need to fly home from or to Whittier, Alaska to catch the tour and cruise, but flights are typically under \$400 per person. If you're interested in cruising longer I have a few clients

who have simply done a northbound and southbound itinerary back-to-back. Fourteen days on a cruise sounds pretty delightful to me!

One final piece of advice: if you're considering an Alaskan cruise this spring or summer, inquire soon. With only 48 sailings going round trip Vancouver, we see accessible staterooms book quickly. Gone are the days when you can simply show up at the pier on the day of embarkation and land yourself a stateroom. Also, the key to a good fare is booking early. American travellers book Alaskan cruises months in advance, and rarely is there enough supply to meet demand with this short cruising season. ■

Amy Billingsley is a travel agent with Expedia CruiseShipCenters Burnaby, where she specializes in accessible travel. She and her husband Jason, a C5 quadriplegic, have also cruised

extensively. Amy also has a blog (www.curbcut.com) where she's able to share information she and Jason wish they'd known before they'd set sail, solutions they figured out along the way, and tips to get the most out of your travel experience. If you have any questions about travel and cruising, or are ready to take the next step in planning your cruise vacation, call Amy at 604.299.7447 or email her at abillingsley@cruiseshipcenters.com.



Accessible BC: Vancouver Island Travel Guide

First-time visitors to Vancouver Island find nature at its finest: beautiful beaches, majestic mountains, old growth rainforests and fresh mountain rivers. But how to know what you can see and experience if you use a wheelchair?

The Vancouver Island Travel Guide is an excellent resource. The second edition of this popular guide provides information about the island's accessible parks and trail systems. It also provides information about a number of accessible hotels, restaurants and other attractions, along with listings of all full service gas stations.

The guide is produced by the Accessible Wilderness Society (AWS), a not-for-profit organization based in Campbell River.

"The idea for the guide came when my wife Judy and I first arrived on Vancouver Island," says AWS founder and president Dan Bauer. "We'd stopped in at a number of the Visitor Centres on our

journey and noticed that information specific to people with disabilities was woefully inadequate at best; at worst, it was practically non-existent. On more than a few occasions we found information about attractions marked with the 'wheelchair accessible' logo, but when we drove the hour or two to the park, we were disappointed to find that the only thing accessible about it was the parking lot."

The guide is just one of several AWS projects. Most ambitious of these is to develop "Canada's first, universally designed resort and campground facility." The society recently secured a tenure for 20+ acres of crown land at Robert's Lake, 20 minutes north of Campbell River.

"Our vision for this property is to build a 16-room resort that is barrier free—a place where family, friends and loved ones can come to enjoy the outdoors regardless of their physical abilities," says Bauer, who became a paraplegic in a car collision in 1985. "I have no illusions of making the entire world a better place. I can, however, take small pieces of that world and help create barrier free opportunities for 'every body' and hope that over time these small pieces will grow to the point where universal design will become the rule rather than the exception."

The *Vancouver Island Travel Guide* is available at no charge at all Vancouver Island BC Visitor Centres. You can also view it online, along with AWS's plans for its Robert's Lake resort, at www.awsociety.org. AWS will also send a hard copy to you for a \$5 charge to cover postage.



AWS President Dan Bauer

ERIN WALLIS PHOTOGRAPHY

We Volunteers!

The third week of April is National Volunteer Week—a time dedicated to recognizing volunteers and promoting volunteerism nationwide. Here at BCPA, we rely on more than 70 volunteers annually to help provide exceptional services to the SCI community across the province.

Since July 2010, one of those volunteers has been Vancouver's Rona Black.

"When I retired I found I had more time on my hands, so I decided to start volunteering," says Black. "BCPA is just one of the organizations to which I donate my time. In times like these, when there are constant cutbacks to worthwhile programs, volunteers are so important to organizations like BCPA, freeing up their staff to concentrate on developing the much-needed programs and services."

Black found out about volunteer opportunities from a relative who was working for BCPA at the time. Her first

job was to help out in the office, doing a bit of computer work, stuffing envelopes, and doing whatever needed to be done. But she quickly saw the impact that BCPA has on the lives of its members and this encouraged her to volunteer more regularly at BCPA events.

"One of the highlights for me as a volunteer was last summer at the Bus Stop Hop, an Amazing Race style event that promotes accessible transport in Vancouver," she says. "Seeing the enjoyment of the participants as they raced around the city using public transit—something that's not an easy task for those in wheelchairs—was just inspiring."

Would Black recommend volunteering to others? "I would recommend anyone who has some free time to volunteer with BCPA or a non-profit organization of their choice. Every little bit of help that you provide is always greatly appreciated. One never knows when you or someone you care about might need



BCPA volunteer Rona Black (right)

these services."

To all of our BCPA volunteers, thank you for your time and efforts—we greatly appreciate your support. ■

BCPA has numerous volunteer opportunities across BC to fit your skills and interests. Visit www.bcpa.org/support-bcpa/volunteer for more information.

48,000 Kilometres By Wheelchair (and Other Arm-Powered Vehicles)

This June, as Rick Hansen celebrates the 25th anniversary of his Man In Motion world tour, another paraplegic adventurer will set off on an epic journey of even greater difficulty.

The ambitious wheeler is Britain's Andy Campbell. A former soldier, Campbell was injured in 2004 during a mountain climbing fall. He barely paused for rehab before resuming a life of adventure—

he's since travelled to far-flung corners of the globe and learned to ski, paraglide, kayak, mountain bike, scuba dive and even rock climb as a paraplegic.

Now he's making final preparations for his most ambitious adventure yet: a 48,000 kilometre, two year trek that will see him cross four continents and almost every type of natural environment on the planet. In the process, he'll use an incredible range of vehicles—from handcycles and kayaks to kite buggies and monoskis.

Campbell will start in London and wind

through Europe, Mongolia and China. He'll then journey from Alaska through BC, before heading down through the USA and Central America and finishing at the tip of Chile.

Aside from the plane ride from China to Alaska and his vehicle support, he'll complete the gruelling journey without any type of motorized assistance.

Roads and sidewalks, let alone a recognizable trail, don't exist in many parts of Campbell's route. So what would drive a man to such lengths?

His modest goal is to raise \$1.5 million to fund mobility equipment for people affected by SCI around the world. But he's also seeking to prove a point: that with the right mobility equipment, people with SCI can thrive—people in western countries can experience real adventure and, more importantly, people in developing countries can elevate their basic independence and health.

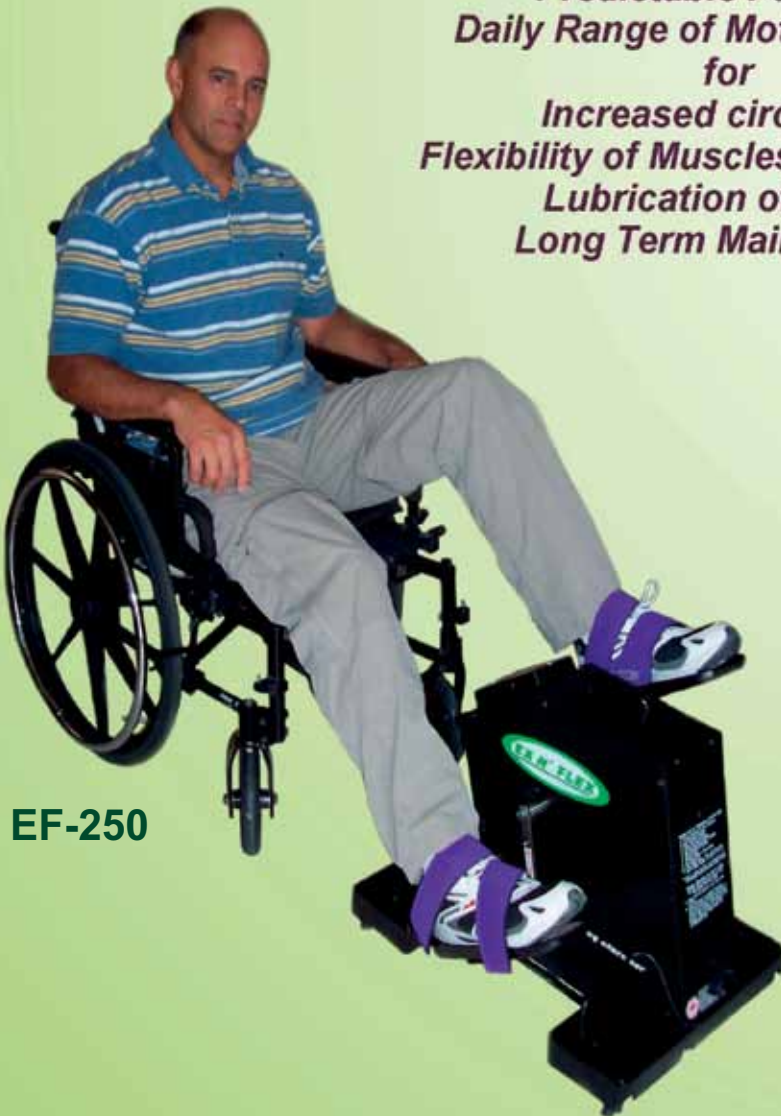
For more information, check out Andy's excellent blog site at www.pushingthelimits.com.



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