

the spin

SPINAL CORD INJURY BC

SPRING 2024

Camper Trailer Round-Up

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contents

SPRING 2024

features

12 Cover Story

With warmer weather on the horizon, we're looking forward to getting back to discovering the best of BC (and beyond) this spring and summer.

16 Caregiving Complexities

As the aging population in Canada grows, more people with SCI and other physical disabilities are taking on caregiving roles for loved ones, leading to unexpected challenges and surprising connections.

19 Matters of the Heart

A new study is underway to find out if there are differences between the male and female heart after SCI.

22 More Pressure Relief

Following up on how a fine white powder is transforming wound care, from pressure ulcers to bone infections, for people with SCI.

departments

4 editor's message

Let's address neurorehab and recovery next.

6 gear & gadgets

New products for daily living.

8 events

Important dates for your calendar.

9 community highlights

Shining a light on partner and staff achievements.

10 peer shoutouts

Giving credit where credit's due.

18 spin doctor

How important is a Pap test?

28 peersay

What do you do if the toilet on the airplane isn't accessible? How can you plan for camping? Our staff shares tips on how you can pee on the go.

29 participate in research

ICORD research projects that need your participation.

30 last word

Build confidence and achieve your health-related goals with SCI BC's new Peer Health Coaching Program.



GOT QUESTIONS?

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Spinal Cord Injury BC

COVER: Ryan Clarkson, SCI BC's Peer Program Coordinator, soaks in the scenery during one of his camping trips.

Let's Address Neurorehab & Recovery Next

In the Summer 2022 issue of *The Spin*, I expressed my pleasure with the provincial government's move to combat period poverty by covering period products for this who need them. In addition to benefiting those who struggle to afford these products, the rationale for the funding logically extends to covering catheters and other essential supplies for folks with SCI.

Over the past year, the provincial government has continued to make a number of encouraging announcements that address poverty reduction, gender equity, and equitable access to health and community services. Universal coverage of prescription contraceptives supports gender equity by removing financial barriers to choices about people's reproductive and sexual health. Expanded coverage for essential diabetes medications and devices means many people with diabetes will not have to face difficult decision about what to sacrifice in order to pay for these essential health-related items.

The rationale for provincial coverage of these things is clear. It should be equally clear that coverage of essential equipment, medication, and services for people with SCI will achieve the same objectives of creating greater financial equity and choices about their health and wellbeing. Add in the fact that these things are also unequivocally essential to stay alive, the time to move on this is now.

I'd like to think we are getting closer to that movement. A recent announcement from the provincial government on a significant investment to support seniors to live independent and healthy lives at home aligns closely with many of the recommendations coming from the BC Rehabilitation and Recovery and BC SCI Care Strategy initiatives SCI BC is part of and which many of you participated in.

As stated in a March 13 news release, BC is investing more than \$354 million over three years in home care and community-based services by recruiting and retaining more health-care workers, improving service delivery, and expanding services for seniors. More allied health professionals (nurses, PTs, OTs, social workers) and home-support workers means "home health clients will have more access to comprehensive and responsive care." The release goes on to state, "New services being added will include support with referral and system navigation, peer support, expanded group activities, social meals and more flexible transportation options."

These are all amongst the core elements identified for creating a coordinated provincial approach to neurorehabilitation that will provide equitable access to health care and community services for people with SCI, stroke, brain injury, and related conditions throughout the province.

The reasons why the provincial government is investing in health and community supports, coverage, and services to improve equity, care, and quality of life for seniors, women, people with diabetes, and others clearly extend to people with SCI and related conditions. It is time to turn attention and resources to investing in the health and quality of life of people for whom neurorehabilitation and recovery is a lifelong journey. Let's make this happen next.



—Chris McBride, PhD, Executive Director, SCI BC



thespin

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We acknowledge that *The Spin* is created on the traditional and ancestral territory of the Coast Salish peoples—Squamish, Musqueam, and Selilwitlh (Tsleil-Waututh) Nations. Our provincial work takes place on the territories of Indigenous peoples who have lived on and cared for the land for time immemorial. We are grateful to work, share stories, and connect in these spaces.

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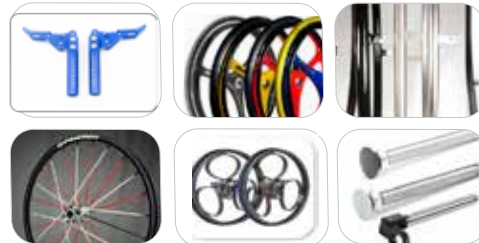
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Innovations

New products, devices, and aids to daily living that might make a difference in your life...

LAP JACKET

SCI BC peer and fashion designer, Chloe Angus, created the Lap Jacket so that wheelchair users can stay stylish and dry in the rain. The Lap Jacket comes with a belt that contains a thumb loop and adaptive Velcro closure, which makes it easier to wear while having a secure fit around your waist. With a durable waterproof material and soft fleece on the underside, you'll feel comfortable enduring cold, wet days. The small case makes it easy to carry on the go and help you feel prepared for any type of weather. Two sizes are available, including a regular fit for people 5'8" (173 cm) and below or the long fit for people 5'9" (175 cm) and above. Get your own Lap Jacket at chloeangus.com.



WHEELIE

The partnership between Intel and HOOBOX Robotics has resulted in the creation of the Wheelie, an AI-powered wheelchair kit that can translate facial expressions into wheelchair commands. The kit can be installed on any motorized wheelchair and only takes seven minutes to set up. You can expect a smooth driving experience as the Intel RealSense cameras can capture and translate 11 different expressions with 99.9% accuracy. Visit Intel.com to learn more about the Wheelie.

MOUTHPAD^

Augment's MouthPad^ is a mouthpiece invention that allows users to control Bluetooth-enabled devices through movement of the tongue over a trackpad positioned on the roof of the mouth. The mouthpiece can learn the tongue's position and movement through a machine learning algorithm that lets you do everyday actions, like sending an email or turning on the lights. The slim, custom-fit design guarantees that wearing the MouthPad^ will not get in the way of speaking. The wet touchpad is designed in a way that saliva or any other liquids would not be a hindrance to the performance of the mouthpiece. Learn more at augmental.tech.





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Be a part of our latest meetup.

Join Caleb Brousseau, one of SCI BC's newest Peer Program Coordinators in Northern BC, for some coffee and conversation starting in April! Swap stories, share experiences, and get your SCI questions answered. Email cbrousseau@sci-bc.ca to get the invite to our monthly meetups in Terrace, held every second Tuesday of the month at 1:30 PM. If you live in the area, say hi to Caleb and your local SCI community! For more of our events, head over to sci-bc.ca/events.



Race with Team SCI BC!

This year marks our 12th anniversary of racing in the Charity Challenge. We have raised over \$600,000 for people living with SCI and we are so excited to participate once again! The virtual race option takes place between June 1-30 and the in-person race happens June 23 in Vancouver. Be a part of Team SCI BC and help us raise funds for SCI BC by emailing Christina at clec@sci-bc.ca to sign-up for the 5K or half-marathon challenge. Visit sci-bc.ca/charity-challenge-2024 for more info.



Don't miss the 2024 Canada Cup.

Attention all sports fans: Wheelchair rugby teams from all over the world will compete for the 2024 Canada Cup right here in BC! The Canada Cup occurs every two years and is the world's most reputable wheelchair rugby tournament. You can catch the action from June 6-9 at the Richmond Olympic Oval and tickets go on sale in April. Can't make the event? An online webcast will be available to stream. Keep an eye out for more details at canadacupwcrugby.com.

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BACK TO OLD ROOTS AT WHISTLER ADAPTIVE

A mountainous congratulations to Sian Blyth for being appointed as the Executive Director of Whistler Adaptive. Blyth returns to the organization following leadership roles at BC Wheelchair Basketball and BC Adaptive Snowsports. Blyth says, "I am as passionate now about inclusivity in sport as I was when I first established Whistler Adaptive Sports Program over two decades ago...I am excited to return to Whistler to lead this incredible organization." Whistler Adaptive has been in operation for over 20 years with a record 3,000+ lessons taught in 18 adaptive sports and is a partner of the Invictus Games Vancouver Whistler 2025, the first ever Winter Invictus Games. SCI BC is thrilled to continue to work with Blyth and Whistler Adaptive to put on events such as our annual Whistler Adaptive Adrenaline Weekend.

Community Highlights



A FAMILAR FACE JOINS THE ORDER OF CANADA

The Order of Canada, one of Canada's highest honours, appointed new members in December 2023, including SCI BC's very own board member, Antonio (Tony) Ariganello! We can always

count on Ariganello, who joined the SCI BC Board in 2011 and is a member of both the Audit and Governance Committees. Currently the President and Chief Executive Officer of the Chartered Professionals in Human Resources of BC & Yukon, Ariganello endows his expertise as a board member for various organization and initiatives. His appointment as a Member of the Order of Canada reflects his intelligence, generosity, and commitment to "advancing national practices and standards in the accounting and human resources professions as a leading financial executive." Well done, Tony!

SAY HELLO TO NEW EXECUTIVE DIRECTORS IN THE BC SCI NETWORK

Wheel good updates from the BC SCI Network! SCI peer Marni Abbott joins BC Wheelchair Basketball Society (BCWBS) as the Executive Director, and Michelle McDonell steps up as Executive Director at BC Wheelchair Sports Association (BCWSA). "Having been involved with BCWBS as a player, coach, and administrator for over three decades, I am thankful for the impact the game has played in my life. It is an exciting time for me to be a leader in this amazing sport," says Abbott. Likewise, McDonell has played a leadership role in her eight years with BCWSA, including heading the Wheelchair Tennis and Bridging the Gap programs. She says, "BC Wheelchair Sports is an incredible organization full of amazing people with an important mission." As part of the BC SCI Network, we are thrilled to work alongside these new leaders towards our shared goal to make BC the best place for people with physical disabilities to live, work, and participate in the community.



Marni Abbott



Michelle McDonell



Trent Seymour



Caleb Brousseau

SCI BC'S NEWEST PEER STAFF

Please give a big warm welcome to Trent Seymour and Caleb Brousseau, SCI BC's newest Peer Program Coordinators in Northern BC! Seymour was raised just outside of Prince George, on his local First Nations lands, with a traditional Dakelh upbringing. He is excited to work with peers in Prince George following his experience assisting at-risk and homeless individuals in Vancouver's Downtown Eastside and working with the Rick Hansen Foundation. Born and raised in Terrace, Brousseau brings a unique perspective on SCI through his lived experience as a paraplegic for 15 years, and now as a quadriplegic. He lives an adventurous and active lifestyle, including earning a bronze medal at the 2014 Sochi Paralympic Games, and looks forward to connecting with peers in Northern BC.



We are abloom with joy in congratulating Kelowna's **SPRING HAWES** on being one of 21 British Columbians to receive the 2023 British Columbia Medal of Good Citizenship. The award recognizes outstanding citizens for their generosity, service, acts of selflessness, and contributions to community life. Hawes is a powerful

advocate in many forms: She formerly worked for SCI BC, coordinating peer events in the Okanagan, and served as a local government councillor. Hawes currently serves on the boards of Interior Health and Accessible Okanagan, championing equity, accessibility, and inclusion in the community. Congratulations Spring Hawes!

Peer Shoutouts

Are you an SCI BC peer with something to shout about? Or do you know a peer who has recently achieved something noteworthy? Send the details to thespin@sci-bc.ca.



A kind-hearted kudos to SCI peer **RYAN YELLOWLEES** for becoming a Registered Clinical Counsellor (RCC)! Upon completing his Masters in Counseling, Yellowlees began offering virtual and phone counselling services to clients across BC and is currently accepting new clients. He specializes in physical disability and physical illness counselling and works from a (Dis)ability Justice, humanistic,

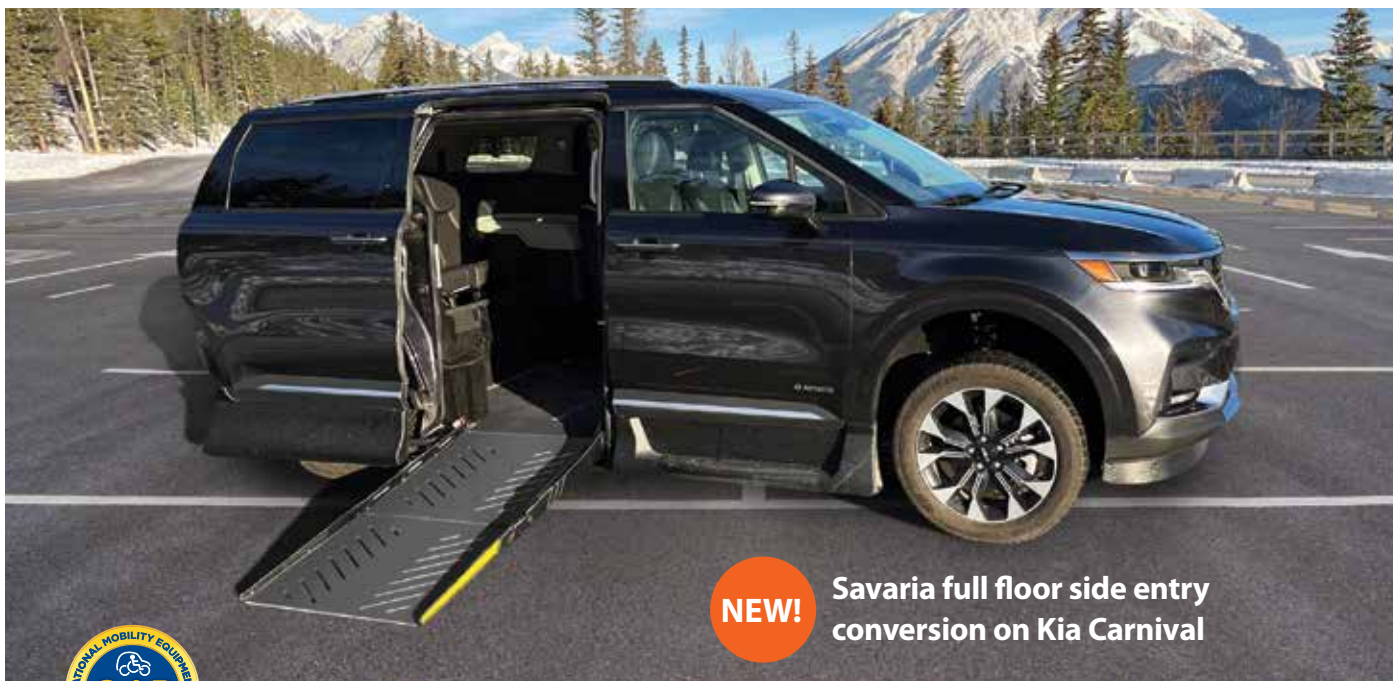
person-centred, and strength-based perspective. We think it's wonderful that people with physical disabilities can receive mental health support from someone with lived experience. You can say yellow to Yellowlees by emailing ryan@icc.care or calling 1-778-743-8187.



A rocking shoutout goes to SCI BC member **SUSAN BAINS** for her passionate advocacy in White Rock. In February, Bains presented a proposal to White Rock city council to make the landmark White Rock pier safer and accessible for all. A specialized and affordable mat could provide a level surface, allowing all visitors to enjoy the pier. She recruited a crowd of fellow advocates to join her in support of the proposal. Bains told Global News, "I want this to be the most accessible, inclusive pier in Canada." And this isn't the first time Bains has brought the issue of accessibility to the city's attention: She was previously turned down by the city's engineering department and came back this time with research to refute their concerns. Now that's what we call pier-sistence!



Best wishes to **VIVIAN GARCIA**, SCI BC Volunteer Peer Mentor, who is wired for success in her new position on the Board of Directors for Technology for Living (TFL). Peers in Surrey likely know Garcia from coffee groups, which she has hosted since 2015. TFL works with people who have physical disabilities and helps them to live as well and as independently as possible. Garcia's enthusiasm and experience make her an excellent fit for her role. She joined SCI BC in 1988 and has stayed involved with SCI BC after working as a Peer Program Coordinator in Vancouver. We are so excited to see Garcia shine in her new role!



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Camper Trailer Round-Up

With warmer weather on the horizon, we're looking forward to getting back to discovering the best of BC (and beyond) this spring and summer. To prepare for the adventures ahead, we talked with SCI BC peers and trailer experts to learn more about the pros and cons of using camper trailers to explore the great outdoors.





“I really love the outdoors and getting out and it’s always something that I did growing up,” SCI BC peer Kimberly Joines says. “My parents are both teachers, so we always just spent the whole summer camping, you know? So, it’s really just maintaining the same lifestyle that I was used to before [my injury].” Joines, who is a two-time Paralympic bronze medallist has always been one to embark on new challenges, and camping is no exception. Between 2014 and 2018 Joines and her boyfriend spent an average of 70 nights per year travelling and camping throughout North America. They travelled everywhere from Moab, Utah and Northern California to Inuvik, Northwest Territories, taking in sights and connecting with friends.

To make the trip to the far North possible, they invested in the nuCamp’s t@b Q camper trailer. “If you’re doing a very large trip like we wanted to do, to go up North, that’s six weeks at least and you can’t cover that distance and set up camp every day in a tent. So we knew we wanted a trailer to log a lot of miles and cover more ground,” Joines says. “We also knew we wanted one with a very large bed and this particular model has almost a king size bed, so that sold us. And when the bed is not set up, we can fit as many as six adults around a decent sized table. So, for a very small trailer, it’s super functional.” The trailer also features a 2-burner glass-top stove, sink, cabinetry, a hot water system, central A/C, and a fridge (although Joines notes that these last two features have been temperamental). nuCamp no longer makes this particular model, but a similar option is their 320 S trailer (pictured in this article). The main

difference is that the 320 S includes a bathroom, and therefore the bed size is smaller than the t@b Q.

When deciding what type of trailer to purchase, Joines researched different models through the lens of independence. “We looked at the layout of a lot of options when we were shopping, and they definitely ended up in this kind of in-between; where you couldn’t really reach anything once you’re in, unless you’re in your chair,” she says. She decided on the t@b Q model because it allowed her to maneuver inside by herself. “I have a leg I can kind of pivot on, so I put my pivot leg inside the trailer and pull myself through the doorway and straight onto the bench seat,” Joines explains, adding that after she transfers, she usually leaves her chair outside if the weather is good or asks her boyfriend to put it in their vehicle. If camping solo, Joines can pull the chair into the doorframe, disassemble it, and store it under the table. “Once you’re inside, you can pretty much reach out to everything in the trailer from the edge on the bench,” she says. “In my early years in a chair, I found tenting worked well because I had a cot and I just wanted to camp, but I do different things now. It’s all about how much work you’re willing to do versus the experience you want to achieve.”

Considering the type of experience you want is the main piece of advice Joines recommends to those interested in purchasing a trailer or starting camping. “We do a lot of mountain biking and that was another one of the main reasons we got the trailer at the time,” she explains. “For most of our camping trips for mountain biking I’d be a shuttle driver, so we needed to be able to transport the bikes but also have a comfortable place to sleep. Having a trail-

er, rather than an all-in-one camping unit, allows us to detach and leave camp set up while we were off using the truck to adventure. Now we also do motor sports, so we can fit motos in the truck or have space for my amTB [adaptive mountain bike].”

If someone isn’t interested in transporting toys or extra camping gear, or if they don’t need the comfort that comes with a contained trailer then it might not be the best fit. “Before the trailer, our set up was a large tent with a big awning off the front. That was really nice for being able to leave my chair out there and protect all of my gear, so there are options based on your recreation goals and interests.”

Learn more about nuCamp trailers: nucamprv.com/tab-camper.



Top to bottom: The 320 S trailer’s bed, sink, and lounge area.



DROPLET Camper Trailer

The DROPLET camper trailer first appeared on SCI BC's radar when peer, Tanelle Bolt, was featured in an article and video highlighting the wheelchair accessibility of the unit. In 2019, Bolt met the owner of DROPLET trailers, Pascal Pillon, and the two bonded over their love of camping and the outdoors. Eager to hear feedback on the trailer, Pillon lent Bolt a DROPLET trailer for a three-week trip to the Yukon in exchange for her suggestions on how to improve accessibility and a review of her experience.

"We discovered with Tanelle that our campers [are at] chair height so transfer

is easy," Pillon says. "The doors are the widest in the industry, making transfer very easy too and the kitchen is only 15" deep, therefore everything is accessible." Bolt recommended a few changes based on her experience, including adding a pull to close the trunk of the trailer more easily, and they have been taken into consideration. "We currently offer a free adaptation for wheelchair users based on their abilities," Pillon explains. "We're now very mindful of accessibility when we design new features. DROPLET is all about offering opportunities for easy and comfortable camping and [we

have] since added accessibility to our design checklist."

If you're not ready to commit to purchasing a trailer quite yet, the DROPLET is also available to rent. Ed Bell, an SCI BC peer, opted for this route a few years ago when he rented a DROPLET to travel through Alberta and Saskatchewan and down to Montana, Colorado, Utah, and Arizona before returning home to BC. "We towed the trailer with our 2016 Honda HRV and had no problems towing it other than a decrease in gas mileage, as expected," Bell says. "Getting in and out of the trailer was not too bad, but if it was mine, I would have some grab bars installed to assist... [at night] we put my chair in a small tent that we would set up as a change room." Overall, Bell says that the DROPLET was a step up in terms of comfort and contained everything he needed in one small package. "It worked [for me] in my 30s, or 40s when my mobility was better; and I was more active. Now in my 60s, I think what would work for me would be a motorhome with a lift."

Learn more about the DROPLET trailer: droplet-trailer.com/wheelchair-accessible.



Trailer Advice

SCI BC's Peer Program Coordinator Ryan Clarkson is no stranger when it comes to hitting the open road. His solo road trips and camping adventures have taken him as far north as Alaska and as far south as the US-Mexican border. Throughout his excursions, Clarkson has experimented with a variety of camp setups and shares some sage advice.

"Always think about what type of camping you are doing and how are your transferring skills?" This will determine what equipment you need and how you prepare. "If you plan to go to more remote locations down service roads, you will want beefier tires to avoid flats," Clarkson says. "But larger tires mean higher ground clearance which means a higher surface to transfer to... and some teardrops will have a six-inch gap [or more] between the

mattress and door which means you have to transfer on to a hard surface, which means your skin is at risk." Over time, Clarkson has developed a keen sense of awareness for these types of considerations and recommends the following when it comes to trailers:

- Learn how to pack your truck and the trailer. A trailer that has been loaded improperly is more likely to cause trailer sway. The weight should be balanced on each side of the trailer, and about 60% of the weight should be toward the front.
- Know what the towing capacity of your vehicle is. Your car might have zero issues towing something around sea level but load it up with camping gear and water and it might not make it over mountain passes.
- Consider your chair. For most teardrop trailers, you are going to have to get comfortable with leaving your chair outside

to the open elements or have a partner to pack it away in your vehicle. Some people don't like the thought of either leaving their chair out in the open for others to see, or having it packed away and not easily accessible in case of an emergency—so think about what you want.

Read more about Clarkson's road trips: sci-bc.ca/road-trip-camping. ■



Ryan Clarkson's camping adventures throughout the US and Canada.



Caregiving Complexities



As the aging population in Canada grows, more people with SCI and other physical disabilities are taking on caregiving roles for loved ones, leading to unexpected challenges and surprising connections.

The most recent Canadian census revealed that the population of those aged 85 or older is one of the fastest-growing age groups in Canada. As of 2021, this age group accounted for over 861,000 people (more than twice the total number recorded in the 2001 census) and is expected to continue to grow in the decade ahead. By 2046, it is anticipated this number could triple to almost 2.5 million people with a concentration of elderly individuals living in temperate BC regions. As of writing, over nine percent of the population in three Vancouver Island municipalities: Sidney, Duncan, and Qualicum Beach are people 85 years or older.

The growth of this population means that more and more Canadians are in need of caregiving support as they face the challenges that come along with aging. For many of our SCI BC peers and staff, this need has impacted them directly as they have had to step into caregiver roles for loved ones. Suddenly, the responsibilities of legal decisions, medical choices, financial options, and complex housing needs fall under their discretion. While this caretaking situation is not unique to people with aging family members, the added component of providing care with a physical disability is.

As Peter Chisholm, SCI BC's Peer Program Coordinator for the North Shore & Sea to Sky Corridor, describes, "There are a lot of parallels. Shortly after injury there is so much going on and almost everything is unknown. Am I going to be able to go back to work? How am I going to be able to care of myself? Am I going to need help? How do I make modifications in my apartment?... There are all those kinds of considerations and that's what my mom and dad are looking at as well now." Chisholm, whose parents are 92 years old, splits caregiving responsibilities with his two siblings in the Lower Mainland and takes on a lot of the emotional labour for ensuring his parent's wellbeing.



Peter Chisholm

"Both my brother and sister are able-bodied so we kind of make it a team effort. I'm lucky in that way, that I can take on kind of more of a moral support role rather than, you know, something more physical like moving house," he explains. "My mom sometimes says, 'You know, I think about you when things are hard because I know how difficult it was for you after [your injury] and I think I can do this too.' As a child to hear your parents say that is kind of funny. There's a role reversal to it. Especially because I've had an injury, I know about home care and these other types of systems, and I can draw on it in some ways." For example, when Chisholm's parents were considering home modification and mobility options, he knew what ramp would be best for their entrance and helped his dad purchase a foldable power wheelchair through the same equipment supplier that he uses. "I talk to [them] about my experiences in rehab, about my loss of independence and how challenging that is, because that is part of their challenge now, you're getting older and you're needing help."

Although having an innate familiarity with the systems in place to support aging loved ones is beneficial, it doesn't automatically mean these systems will work in your favour. Heather Lamb, SCI BC's InfoLine Services Lead, experienced this paradox first-hand when trying to take a HandyDART in Prince George. Lamb, who provides care for her aging family members and has a visual impairment, is both a registered HandyDART client and a HandyDART attendant for her loved one.



Heather Lamb

However, as she discovered one day when trying to accompany her family member to a doctor's appointment, HandyDART's policy states that "An attendant is a person who will provide additional assistance inside the building, with stairs, or if you have special requirements beyond the accessible door. Attendants must be an able-bodied adult over the age of 18 years and they will travel free of charge on HandyDART. Other registered HandyDART customers cannot travel as attendants." This means that Lamb cannot be an attendant for her loved ones; despite being one of the primary caregivers in every other situation.

The conundrum of being a caregiver while also not being technically allowed to be one is challenging for Lamb. "It brings up the whole idea of, well, who is a caregiver? What abilities does a caregiver have to have in order to be a caregiver? I find it fascinating because I'm actually better at caregiving than [other people] because I work in the system," she says. "The only reason that I signed up for HandyDART myself was to go to one location in the city in the winter that has no public transit access. I don't want to lose that, but I also don't want to lose the ability to go places with my [family]. I'm the medical decision maker so I need to be there."

Lamb's situation can be extrapolated to other SCI BC peers who act as caregivers. For instance, Lamb recalls an SCI BC peer who is the main driver for their family—shuttling and accompanying aging family members to and from appointments—but who is also quadriplegic and requires tie downs in their car. What alternative transportation op-

tions would allow the peer to travel safely while also acting as a caregiver if their car is unavailable or needs repairs? Housing is another major concern for aging adults as they face new mobility limitations or cognitive decline. "For people with disabilities it's not as simple as just move back to where your parents are to take care of them," says Lamb. "There may be no housing available or no care for yourself or no job or whatever. It's a much more nuanced discussion."

At the moment, we don't have all the solutions to these important issues, but what we do know for sure is that our peers have a tenacity to adapt, and SCI BC has the resources to help them do so. "There's no manual for how to do this because everybody's situation is so different," Lamb says. "But I would say the biggest resources would be to know the home and community care systems and to know what the eligibility is for different types of care, as well as some of the limitations within our current system and the accessible housing options." A good place to start building this knowledge is SCI BC's InfoLine and the SCI Info Database. "I refer people to the InfoLine all the time. It doesn't matter if it's a peer or professional or clinician," Chisholm says. "And just have a look through the database because if you're interested in a topic related to spinal cord injury or disability in general, I mean you go in and search, and you're going to be amazed at the information you find."

Above all, Lamb stresses the importance of speaking to your loved ones about their needs and finances. "If a family is selling their home to move into another situation, they're going to have more flexibility than somebody who's been living on a pension or PWD. They simply don't have the same options because of finances. So, I always ask about finances, because it determines what types of answers [the InfoLine] can realistically give."

In addition, we recommend visiting SCI BC's Marketplace for accessible housing listings, reading the CSIL webpage, and checking out our new Aging with SCI program. The program is for SCI BC peers who are aging and therefore may also be dealing with parents or other family members who are aging too. It's a good place to talk things through and work through challenges.

"For me, I think you really need to respect people's personal agency," Chisholm says. "They have thoughts and desires, and they make decisions that might seem baffling at times, but it's meeting their needs. It's not a tragedy. [My parents] lives have been full, and I've had so many wonderful experiences with them. They've lived independently into their 90s, it's just a wonderful story, right?"

To learn more about caregiving, ask questions, or get advice on your particular situation you can call SCI BC's toll-free InfoLine at 1-800-689-2477 or email info@sci-bc.ca.

Other resources mentioned in this article include SCI BC's Marketplace (sci-bc.ca/marketplace), CSIL (sci-bc.ca/csil), and the Aging with SCI program (sci-bc.ca/aging). ■

ask the SPIN DOCTOR

I haven't had a Pap test since my injury a few years ago and I'm 40 now. I'm not sure how it will even work when I can't transfer myself to an exam bed. Can I just skip it?
– Renee in Cranbrook



To answer this question, we reached out to Dr. Lily Proctor, Medical Director of the Cervical Cancer Screening Program at BC Cancer, and a Gynecologic Oncologist at BC Cancer and Vancouver General Hospital.

The purpose of cervical screening is to detect cervical precancers and early cancers that can be treated and cured. This is not a test you should skip! Anyone with a cervix, including women and TTGD (Two-Spirit, transgender, and gender diverse) people between the ages of 25 and 69 should participate in cervical cancer screening.

Until recently, the primary test in British Columbia was a Pap test. As of January 29, 2024, you can order a highly accurate cervix self-screening kit. You can self-screen in the comfort of your home or at the office of a health-care provider.

The cervix self-screening kits tests for human papilloma virus (HPV), the virus that causes cervical cancer. During a Pap test, a health-care provider inserts a speculum into your vagina and removes cells from the cervix to test for changes that have been caused by HPV. Cervix-self screening can detect the presence of high-risk types of HPV before cell changes have occurred and does not require a sample of cells from the cervix. Testing for HPV detects cervical cancers earlier and faster than testing with a Pap test. We also have more confidence in a negative HPV test, which is why the recommended testing interval is every five years, instead of every three years for a Pap test.

To be able to complete the cervix self-screening swab, you need to be able to place the swab into your vagina and rotate it for 20 seconds. The insertion of the swab is similar to how you would insert a tampon, though the swab is much smaller. If you are unable to complete the test yourself, you can get a support person to help with sample collection at home or ask a health-care provider to collect a sample for you.

Vaginal samples collected by patients have been shown to be just as accurate as those collected by health-care providers. If collection hasn't been done properly or the result is invalid, BC Cancer would let you know that sample collection needs to be redone.

BC Cancer will mail you a letter when you are due for cervix screening. You and anyone who has never been screened can request a self-screening kit by phone at 1-877-702-6566 or online at screeningbc.ca/cervix. Kits are mailed in non-descript envelopes and include simple instructions and a prepaid return envelope.

Results will be sent by mail and/or online to you and your health-care provider within four to six weeks from the time the kit is completed. A Pap test or colposcopy may be recommended for you if you test positive for HPV, depending on the type of HPV detected.

A positive HPV test does not mean you have cervical cancer. HPV is the most common sexually transmitted virus, and most people will contract it at some point in their lifetime. Usually, HPV clears up on its own. Only long-term infection with high-risk HPV can cause pre-cancerous changes to the cells of the cervix, which can develop into cervical cancer if undetected and untreated. A positive HPV test helps identify people at risk of developing abnormal cells of the cervix, so those cells can be detected and treated early to prevent cervical cancer.

If you test positive for HPV, it's important that you reach out for follow-up care and treatment. If you don't have a primary care provider or nurse practitioner, you will be connected to a clinic in your community that can provide follow-up care and support. Help us in our efforts to eliminate cervical cancer in BC!

SCI BC's Associate Director of Service Delivery responds:

Many people with SCI who require gynecological care don't have access to a clinic with accessible bed for exams such as a Pap test. This HPV self-test may offer a more accessible way to keep up with cervical cancer screenings. Have you tried it? Tell us how accessible it was for you: jmaffin@sci-bc.ca.

Matters of the Heart



A new study is underway to find out if there are differences between the male and female heart after SCI.

What would you think if I told you that, until recently, scientists and physicians generally assumed that women's bodies worked like smaller versions of men's? Decades of scientific research has been mostly based on male physiology, guided by the assumption that—aside from the obvious reproductive differences—male's and female's bodies function in much the same way.

But as it turns out, there are differences—and they do matter. And while the scientific community has made progress in understanding these differences and their implications for female's health, a significant sex and gender gap persists.

For example, between 2009 and 2020, only 5.9% of research funded by the Canadian Institutes of Health Research (Canada's federal funding agency for health research) looked at outcomes specific to women. And the research that does exist often overlooks differences in how male and female experience a wide range of conditions, resulting in a

limited understanding of female's symptoms and outcomes.

In the SCI community, research investigating sex and gender differences is even harder to come by. According to Dr. Alexandra Williams, a Postdoctoral Fellow at UBC's Faculty of Medicine and the International Collaboration on Repair Discoveries (ICORD), one of the main challenges for researchers who study SCI is the relatively smaller number of women compared to men in the SCI population. There are about 86,000 people with SCI in Canada, and one-quarter of them are women. "The reality is that there's a larger proportion of males in the SCI population, so it can be harder to find enough females for research studies," says Williams.

Even so, the low ratio of women to men in the SCI population doesn't fully explain the underrepresentation of women in SCI research. For example, a review of research on SCI and heart system health published in 2021 showed that women represent only one-eighth to one-quarter of study participants. And in many cases, the authors of

the review noted, females are excluded from participating in clinical research (in favour of easier-to-recruit males) to make the study population more homogenous, and thus, easier to draw conclusions from. As a result, we know a lot more about the physiology of males with SCI compared to females.

Williams drew similar conclusions from a review she led that focused on studies that used echocardiography, or heart ultrasound, to assess the impact of SCI on heart function. "We did a systematic review back in 2019, and from all the data we accumulated through those studies, about 5% of those data were from females. It was a very small percentage," she explains. "And we thought, 'Okay, there's a huge gap in knowledge here.' We're not even scratching the surface of understanding female physiology in the context of SCI."

This gap in knowledge is what led Williams to the world of SCI research. Before joining ICORD, Williams' PhD research focused on understanding why the heart differs in its function and structure between males and females who are healthy,

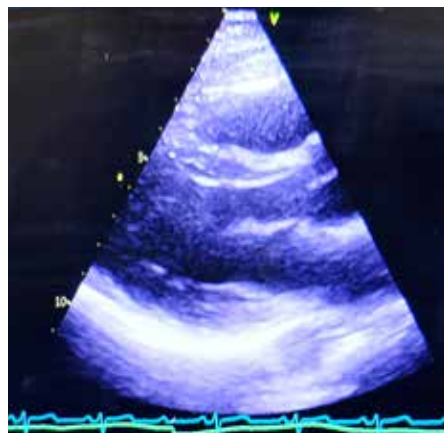
uninjured, and without any cardiovascular disease. According to Williams, there are differences in the size and shape of male and female hearts that are independent of body size. For instance, males tend to have larger hearts relative to the size of their body compared to females. Another key difference lies in how male and female hearts respond to stress. When standing up from a seated or lying position, females regulate their blood pressure in different ways than males, and can be more likely to faint as a result.

“But then the question is, ‘Why are females responding differently?’” says Williams. “And a key thing that we found in my PhD studies was that differences in male and female heart function are likely linked to their autonomic nervous system.” The autonomic nervous system regulates involuntary body processes—the processes that we can’t consciously control—such as heart rate, blood pressure, and breathing. It was this finding that prompted Williams to extend her PhD research to the SCI population.

“We’re bringing this research to a population that has a hugely impacted autonomic nervous system,” she explains. “And we’re wondering: Do those differences continue to occur in males and females with SCI? What are the repercussions of that loss of neural control of the heart? And will those baseline differences between males and females affect those outcomes?”

Williams is working with UBC Associate Professor and ICORD Principal Investigator Dr. Chris West, who studies the impact of high-level SCI on the heart. What we know from research in this area is that SCI at or above the mid-back impacts the way a person’s brain communicates information to the heart through the autonomic nervous system. In the case of high-level SCI, the heart and cardiovascular system can’t respond as adequately or effectively to a stressor, such as a change in posture or transitioning from rest to exercise, as they would prior to the injury.

The result, as many of our readers know, is that blood pressure management can be a challenge after SCI. People with SCI are also at increased risk of developing heart



Ultrasound heart scan of a participant.

disease compared to the general population. Given the differences between male and female hearts that we know exist before injury—and their links to the autonomic nervous system—research focused on how male and female hearts function after SCI provides crucial insight into gender-specific treatment and management of issues related to the heart.

With that end goal in mind, Williams and West are conducting a study to examine if there are differences in the hearts of males and females with SCI between the C4 and T6 levels when compared to the differences that exist between uninjured males and females. This will be the first study to investigate if there are differences between the male and female heart in people with SCI, and how potential sex-related differences play a role in blood pressure control.

“It’s a pretty straightforward study. We have the individuals come into the laboratory at ICORD [in Vancouver] for just for a single day. The visit lasts about an hour and a half to two hours. We show them the equipment and measure their body weight. And then we have them transfer onto a tilt table for the tests,” says Williams.

The tests involve basic ultrasound scans of the heart to look at its size, shape, and function. At the same time, blood pressure is monitored using a standard arm cuff. The tests begin with the participant lying flat, allowing the research team to assess the heart at rest. From flat, the table is gradually tilted upwards so that the participant’s head is higher than their feet. Then the table is returned to a flat position

before being tilted downwards so that the participant’s head is lower than their feet. Throughout this protocol, the research team continues to take scans and monitor blood pressure to examine how the heart responds to the changes in posture.

The research team has also worked to create a safe space for females who want to participate. “I’m the person doing the ultrasound testing,” says Williams. “And that is really helpful for women who are coming in because they often feel a little bit more comfortable with a female who’s scanning.”

The study includes four comparison groups: males with SCI, females with SCI, uninjured males, and uninjured females. Data collection is currently underway, and Williams is actively seeking males and females who have been living with SCI (between the C6 and T4 levels) for at least one year to participate in this study. To be eligible, you must be between the ages of 18 and 45 with no symptoms or history of heart disease. You’ll also need to be able to travel to the Blusson Spinal Cord Centre at ICORD (818 West 10th Avenue, Vancouver) for the assessment.

“I think this study is a really great starting point because we’re understanding not just resting function, but also function under stress, which is really important for understanding day to day challenges with blood pressure control,” says Williams. “We’re also hoping that this research will provide a foundation for understanding cardiovascular dysfunction, treatments, and long-term risks associated with SCI that could potentially be different in men and women.”

For Williams, this study is the first step toward understanding not just female heart function, but female physiology more generally, in the context of SCI. It’s about closing the sex and gender gap, one piece of knowledge at a time.

To learn more about the study, visit icord.org/studies/2022/10/cardiac. You can also reach out to Alexandra Williams at alex.williams@ubc.ca for more information and to sign up. In the meantime, we’ll keep tabs on how the study progresses and report back when the findings come to light. ■

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1. A Multi-Centre Clinical Investigation to Assess the Performance of GentleCath™ Glide intermittent catheters. Study U378 GentleCath™ Glide Final Report. July 2018. In vitro data on file. Convatec Inc.

2. Pollard D, Allen D, Irwin N J, Moore J V, McClelland N, McCoy C P. Evaluation of an Integrated Amphiphilic Surfactant as an Alternative to Traditional Polyvinylpyrrolidone Coatings for Hydrophilic Intermittent Urinary Catheters. Biotribology. 2022;32(Dec 2022):100223.

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More Pressure Relief

Following up on how a fine white powder is transforming wound care, from pressure ulcers to bone infections, for people with SCI.

In the early days of 2021, as the rest of the world hunkered down for what would be the first full winter of the COVID-19 pandemic, Vernon resident Dwight Negraiff had an infection of a different kind on his mind. For the past two years, Negraiff, who is quadriplegic, had struggled with a stubborn pressure ulcer that just wouldn't heal.

"My doctors and nurses, they tried every type of medicine and vacuum pump and everything that they could think of, to try to get it to heal, and it just would not heal," recalls the 57-year-old.

It wasn't until his wife was flipping through the Winter 2020 edition of *The Spin* that the couple learned about an innocuous white powder, developed in the UK, that showed serious potential for the treatment of pressure ulcers. The cover story (titled 'Pressure Relief') introduced readers to Amicapsil (also available as Amicapsil-SCI with use information specific to SCI), a compound that uses Micropore Particle Technology, or MPPT, to "pump" the toxins and enzymes secreted by infectious bacteria to the surface of the wound, where it can be removed. The result is an optimized immune system response and a more balanced microbiome, allowing healing to occur.

Soon after, Negraiff sent an email to Willingsford Healthcare, the company that produces Amicapsil. Following a brief exchange, during which he shared a short description and photos of his wound, the company estimated how much Amicapsil he would need and shipped it to his home in Vernon. It didn't take long for him to see results.

"My wife administered [the Amicapsil] and after two weeks, we saw significant improvements. By the time we ran out of the product, the wound was basically gone. My doctors and the nurses were all completely shocked," says Negraiff. "I'd had that pressure ulcer for over two years. [Amicapsil] healed it, and it's never come back."

How Pressure Ulcers Cost Us

If you've had an experience like Negraiff's, then you know that pressure ulcers are a serious concern for the SCI community. Globally, about one in three people with SCI live with pressure ulcers, and the costs are staggering—for both the person with the pressure ulcer, and the healthcare system. Pressure ulcers are difficult to heal, often resulting in prolonged bedrest. The experience can be isolating and reduce quality of life, negatively impacting both physical and mental health.

The financial cost is just as astounding. A study published in 2018 put the lifetime cost of a chronic pressure ulcer requiring hospitalization in Ontario at \$98,500 for a single patient. In 2024, that cost would be about \$118,400. Extrapolating from these estimates, the total cost of treating pressure ulcers among patients with SCI in Canada over the course of their lifetime would come in at a whopping \$3.4 billion dollars—and that's not including the cost of community care. Outside of the hospital, pressure ulcers can cost about \$13,500 per month for a single person, with some patients requiring ongoing treatment for months or years at a time.

The reason behind these staggering costs—physically, emotionally, and financially—is that standard treatments for non-healing chronic wounds like pressure ulcers just aren't working. Standard treatments often include gels and absorbent dressings for non-infected ulcers and topical antibiotics or antiseptics for infected ulcers. Bodies such as the UK's National Institute for Health and Care Excellence (NICE) and the US Food and Drug Administration (FDA) have explicitly stated that systemic antibiotics and antimicrobials are ineffective for treating pressure ulcers, and NICE has gone so far as to explicitly state that these treatments should not be used. But whether it's dogma, tradition, or a simple lack of alternatives, these treatments remain common practice.



Amicapsil applied to a wound.

An Unmet Medical Need

According to the FDA, wounds not healing naturally constitute an "unmet medical need" due to the lack of effective treatments. That's why technologies like MPPT, or Amicapsil, have the potential to revolutionize wound care, especially for people with SCI.

“People with SCI suffer from immunosuppression because the nervous system is damaged and can’t tell the immune system where to send the immune cells to clean up the damage and start the healing process when an injury occurs,” explain Jeanette and Frank Sams-Dodd, founders of Willingsford Healthcare. “In fact, studies have shown that SCI results in a 50% reduction in the number of immune cells that respond to a wounded area. As a result, it’s much easier for infectious bacteria or anything else to take over control. And so, in practical terms, people with SCI have impaired wound healing and reduced ability to fight infection.”

If pressure ulcers are not healed quickly, they can be particularly dangerous for people with SCI. Osteomyelitis, an infection of the bone, can develop in as little as two weeks in a serious pressure ulcer. On top of the prolonged periods of bedrest and low quality of life accompanying a typical pressure ulcer, osteomyelitis can lead to sepsis and recurring hospitalizations. And once the infection is in the bone, it’s much more difficult to remove.

“The problem is that if a wound is not closed rapidly, it can penetrate into muscle. And once that happens, there’s nothing to prevent it from reaching the bone. Then you have the risk of osteomyelitis, which can only be treated with surgery. And the result is that 10 to 12% of people with SCI die as a direct consequence of the pressure ulcers,” explains Dr. Frank Sams-Dodd. This is why the Sams-Dodds are on a mission to effectively treat pressure ulcers; time is of the essence to close the pressure ulcer and prevent osteomyelitis from developing in the first place.

A New Way Of Doing Things

You might be thinking to yourself, “If Amicapsil has the potential to revolutionize wound care, how come my doctors and nurses aren’t using it?” The short answer is: Amicapsil isn’t approved for professional use in Canada—at least, not yet. But it can be imported to Canada for personal use, and it’s been approved for professional use in several other countries,

including the UK, Australia, New Zealand, and the EU.

These approvals are supported by a large (and growing) body of research evidence supporting the use of Amicapsil (and SertaSil, a form of MPPT used for veterinary wound care) in humans and animals across a variety of wound types, from trauma and surgical wounds to diabetic foot ulcers, venous leg ulcers, and, of course, pressure ulcers. For those of you that would like to take a deeper dive into this research, you can find the highlights in the Winter 2020 edition of *The Spin*. The bottom line: MPPT heals wounds significantly faster than other treatments.

However, until recently, a limitation of the existing research supporting the use of Amicapsil was that, aside from case studies, people with SCI had yet to be studied. But new clinical research published in the journal *Frontiers in Medicine* shows just how effective Amicapsil is for treating wounds and pressure ulcers in people with SCI.

The study, a joint effort of the Willingsford Healthcare, the National Spinal Injuries Centre at Stoke Mandeville Hospital, and the Duke of Cornwall Spinal Treatment Centre at Salisbury Hospital, examined the use of Amicapsil as a treatment for 44 wounds and pressure ulcers in 25 people with SCI. Given the lack of effective treatments to serve as comparators and the risks involved with leaving a wound untreated (as would be the case in a placebo group), the study investigated Amicapsil use under real-world conditions.

“You’re not allowed to use placebo or comparators if you know that you are exposing the person in the study to irreversible morbidity or death,” explain Jeanette and Frank, who are study co-authors. “We knew that the existing treatments were not considered effective in treating pressure ulcers, so we could not ethically ask a patient to be in the comparison group.”

Delivered via telemedicine in community care, the researchers simply observed the effects of the Amicapsil and compared the findings against outcome data available in other published studies. “We didn’t put in



any extra parameters or measurements, we simply just recorded when people were using Amicapsil, what happened to the wound—did it close, did it not close—how long it took, and how much Amicapsil was needed,” says Frank.

A Treatment That Works

Because Amicapsil functions in part by harnessing a person’s own immune cells to promote healing, there was a possibility that Amicapsil might not work well in people who are immune compromised, including people with SCI. But the results of the study showed that this was not the case. In fact, daily use of Amicapsil closed all acute and chronic pressure ulcers in the study.

“The results of our study show that the number of days to close [the wound] simply depends on the severity and age of the wound, but the important part was we had the 100% closure rate. As long as we [treated the wound] before osteomyelitis was present, we were able to close the wound,” says Frank.

What’s more, in wounds acting as a draining fistula from an underlying source of infection, such as osteomyelitis, Amicapsil was able to remove the soft tissue infection in as little as 2.5 months, significantly reducing the size of the wound and the risk of sepsis. As a result, patients spent less time in hospital, required less bed rest, and reported greater wellbeing.

“What Amicapsil does is to reduce the overall level or quantity of infection in your body. And an infection in your body releases toxins into your blood. So, the smaller you can keep any infection that’s

chronic, the less toxins you will have in your blood. Toxins in your blood is called toxemia and it takes away your energy and makes you feel miserable,” explains Jeanette. “And while a draining fistula resulting from osteomyelitis won’t completely close, what we’re getting back from people is that [the Amicapsil] makes a very, very big difference because they don’t need bed rest and they get their energy back. They can exercise, they can go out, they can play an active part in the family, or maybe hold a job. You still need to treat the draining fistula every day, but it gives a completely different quality of life.”

The effects of Amicapsil on soft tissue infections may also have diagnostic value when it comes to identifying the presence of osteomyelitis. Research shows that current diagnostic tools, including MRI, CT, and X-ray scans, are not very effective for diagnosing osteomyelitis in people with SCI. But if a wound that is being treated with Amicapsil refuses to close, it could indicate an underlying source of infection. Visible markers on the wound surface could also be used to indicate if osteomyelitis is present.

According to Frank, there isn’t a downside to using Amicapsil for pressure ulcers, whether or not osteomyelitis lies underneath. “If someone comes in with a pressure ulcer, you want to treat it immediately because it may still just be a wound. You don’t want to spend too much time getting an MRI because by that time it could already have developed osteomyelitis. And if it is osteomyelitis, you would want to use the Amicapsil anyway to reduce the soft tissue infection and risk of sepsis.”

While still in the preliminary stages, the Sams-Dodds are working on new research to better understand how Amicapsil can be used to support the treatment of osteomyelitis, and how it might serve as a diagnostic tool.

Cheaper And Easier

Another important highlight from the study published in *Frontiers in Medicine* showed that, in addition to being safe and effective, Amicapsil can considerably re-

duce the cost of pressure ulcer care for people with SCI. Compared with standard care, per-wound cost savings of 51% to 94% per wound (depending on wound severity and age) resulted from successful wound closures and controlling soft tissue infection linked with osteomyelitis.

The telemedicine approach also lowers costs by reducing the demand placed on nurses and other healthcare providers. Amicapsil can be administered independently at home and does not require bed rest, enabling self-care. “The fact that it can be delivered by telemedicine means that you don’t have to wait. If you have someone who can help you or you can apply it yourself, you don’t have to wait at home for the nurse to come. You can choose your own schedule,” explains Frank.

“It provides a huge change towards equal access because anyone can help to treat the wound. We’ve even had a patient who had help from his 10 year old daughter, she did it better than anyone else,” adds Jeanette. “You don’t need to be a wound expert.”

In fact, the telemedicine approach takes place entirely over email. All you need is phone, tablet, or computer with a camera and an internet connection. “Normally, what happens is that people contact us, we ask them to send a picture of the wound and information on the wound age, how it has been treated, and whether there are underlying issues. Then based on that, we tell them what to expect. And then we can send [the Amicapsil] to them. And then if they wish we can help them use it correctly so that they get the maximum benefit from it,” says Frank.

Treatment consists of first rinsing the wound with tap water, preferably in the shower or otherwise with a squeeze bottle. Excess water is removed and, while still moist, Amicapsil is applied directly to the wound in an unbroken layer. The wound can be left uncovered, or covered with a piece of woven, cotton gauze, which will allow airflow and evaporation. The duration of treatment depends on the severity of the pressure ulcer and the healing progress.

“And people know that their wound is being looked after,” says Jeanette about the telemedicine approach. “And that’s one of the reasons why they keep sending pictures, because it also gives them the peace of mind that, ‘Okay, these people are actually checking my wound every single day, ensuring things are moving in the right direction.’”

Real World Evidence

While Amicapsil use has yet to become commonplace in Canada, satisfied clients like Vernon’s Negraiff say it’s a no-brainer for anyone dealing with a pressure ulcer. “Don’t be afraid to try it. Every pharmaceutical drug out there has side effects. And everybody’s body is different. I mean, just the quality of life has changed for me not having a nurse come over every two days, changing bandages on my butt, having a vacuum pump attached to my butt, having to go to the hospital and see the plastic surgeon and all the other BS,” he says.

In the UK, where Amicapsil is more widely used, the British Spinal Injuries Association surveyed people with SCI about their experiences using Amicapsil to treat pressure ulcers. Independently confirming the findings of the *Frontiers in Medicine* study, the survey results showed that every respondent—a total of 41 people reporting on 49 pressure ulcers—reported that their pressure ulcer(s) closed following MPPT treatment, and 95% of respondents rated their experience using Amicapsil as positive or highly positive and 0% negative. Likewise, respondents with a draining fistula reported that Amicapsil effectively

Susan Ormsby



controlled soft tissue infection resulting from osteomyelitis.

Among the UK-based clients whose lives have been impacted by Amicapsil are Susan Ormsby and Steven Parry. Both Ormsby and Parry are managing open wounds with osteomyelitis, and both have reported significant improvements since beginning treatment with Amicapsil.

Sixty-four-year-old Susan Ormsby of Glasgow, Scotland, was born with spina bifida and has been using a wheelchair full-time since the age of 50. She has syringomyelia, a fluid-filled cyst in her spinal cord that causes weakness and loss of sensation. So, when she fell off her wheelchair and dislocated her elbow, she wasn't aware that she'd been injured until much later.

"It wasn't until I became aware that my arm was in pretty bad shape that I went and got an X-ray. And it was too late to do anything with it because osteomyelitis had set into the bone. And a whole lot of pus had formed, and it burst out through the skin," she says.

Ormsby estimates that the open wound on her elbow was about five to six centimeters in diameter. Her doctors told her that if the infection in her elbow couldn't be controlled, the only treatment option would be amputation—which, naturally, she wanted to avoid.

"So, after about nine months of having this terribly leaky arm and I mean, it was very, very leaky, I managed to find out about Amicapsil. And within 12 days, we noticed—now I'm saying 12 days after nine months of a big gaping hole—we noticed that the skin was starting to heal round-

about, and the hole was getting smaller to the point now that is just a very small pin-head," says Ormsby. "And that will never close because they want that to stay open anyway, so that it can drain the fluid from the bone."

Amicapsil not only saved her arm, but it's also improved her overall physical health. "What used to happen was every six or seven weeks, I would end up in hospital getting IV antibiotics, and since I've used the Amicapsil I have not needed to be going into hospital for anything like that. Definitely my whole system is better," she says.

The benefits extend to her mental health and quality of life. "The district nurses used to have to come in three days a week. Now they come in once a month, just to check that I'm happy and that everything's going alright," she explains. "You feel as though you can go on holiday without thinking, 'I might need treatment.' So, it's a big bonus that way too."

Greater Manchester's Steven Parry also has seen how treatment with Amicapsil can change a life. After having surgery for a spinal arteriovenous malformation or AVM (a tangle of blood vessels on or in the spinal cord) and becoming a full-time wheelchair user in 2015, Parry was discharged from hospital with a pressure ulcer on his sacrum that deteriorated rapidly.

"I was having it treated at my local medical center and over a period it started to deteriorate quite rapidly. And I became really poorly and ended up with a pressure sore that was a grade one to two that quickly escalated into a grade four," explains Parry. "And what hap-



Steven Parry

pened was I ended up in hospital with sepsis and osteomyelitis."

He underwent surgery to remove the bone infection, but the wound still wasn't healing. "I was virtually bedbound for close to two years, having nurses come every day to change my dressings," says Parry.

None of the treatments helped to remove the infection or heal the wound, and some treatments, he says, actually made the issue worse. He wound up back in hospital several times as a direct result of the osteomyelitis. That's when he decided to try Amicapsil.

"My wound was horrendous to start with, very deep and infected, and it went from a big hole to more or less a tiny pin-hole using the Amicapsil," says Parry. "My aim was to keep me out of hospital, keep me safe, keep me sepsis-free. You know, reduce the flare ups of the osteomyelitis. And since I've been using Amicapsil I've not been in hospital, I've not had to have constant antibiotics, and I've not had to have any more surgery. It's just changed my life completely."

The Challenges That Remain

Despite the success they've experienced using Amicapsil, a key challenge that Negraiff, Ormsby, and Parry all highlighted is the cost. Amicapsil is approved for use as a medical device, not a pharmaceutical. This means that there is no insurance coverage for the product, and users must pay for it themselves.

"My insurance company wouldn't cover [the \$600 cost] because it wasn't approved. But they said in two years or three years,



Susan's open wound before (left) and after (right) using Amicapsil.

The Science Behind Amicapsil

If you missed our last article about Amicapsil, you might be wondering, “How does Micropore Particle Technology (MPPT) actually work?” To explain, we need to take a closer look at our skin—or, more specifically, what’s living on our skin.

In healthy skin with a naturally healing wound, there is an established, well-functioning population of microbes. They live inside a protective biofilm where they collaborate as a microcommunity. This is called a microbiome. The microbiome collaborates with the body’s immune system to keep the skin and wound healthy.

“When you look at a wound that is healing, you have this diverse, rich population of different types of bacteria, fungi, and viruses that directly help the immune system in order to prevent infection. And infection occurs when one or a few species have taken over control of the wound,” explains Frank Sams-Dodd.

“You have to think of it as a synergy. So, in healthy skin and healthy wounds, the bacterial population is constantly communicating with your immune system, and the immune system is policing the population so that everybody keeps at the right levels and the right composition, and nobody takes over control. So, the immune system is in control, but it’s always in synergy with the microbes,” adds Jeanette Sams-Dodd.

When a small number of microbes “take over” control of the wound, they secrete toxins and enzymes that prevent the immune system from doing its job. This includes both disarming the immune cells and reinforcing the “protective” biofilm so that the immune cells can’t access the wound’s microbiome. The infectious toxins and enzymes exist in the tissue, exudate (fluid from a wound), and pus.

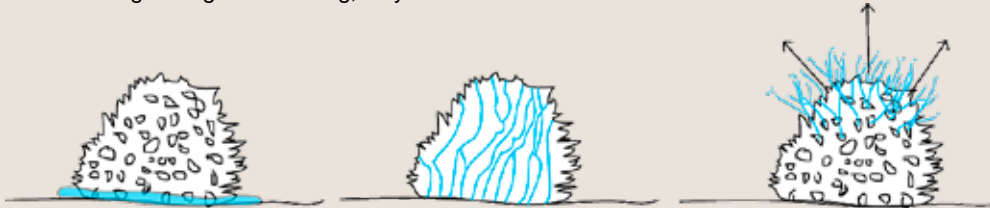
What happens when you apply the Amicapsil is that it draws the exudate to the wound’s surface, where it evaporates, through tiny pores. The pores are so tiny that they can produce a very strong capillary force. It’s the same thing that happens when you leave a straw in a glass of water—the force of adhesion holding the water molecules together and to the straw is stronger than the force of gravity, and forces the water up the straw. The smaller the pores, the stronger the forces.

These capillary forces do two things at the same time: They create holes in the biofilm that allow the immune cells to access the microbiome, and they suck away the harmful toxins and enzymes. The result is that the immune cells are now working and have access to the biofilm, where they can restore the diversity of the microbiome and promote healing.

“It’s a very different mode of action compared to antimicrobials, which try to kill everything,” says Jeanette Sams-Dodd. “When you use antiseptics, for example, iodine and silver, they don’t just kill the bacteria, they also kill the immune cells and the new tissue cells that the body are making in order to heal the wound. Whereas MPPT works in tandem with the immune system to support it without killing anything.”

And because there are no antimicrobials involved in Amicapsil, there are other benefits as well. For example, Amicapsil is effective against antimicrobial-resistant wound infections, but it won’t contribute to antimicrobial resistance. And unlike antimicrobials, the components of Amicapsil are non-toxic and will not cause pollution or contribute to climate change.

“It’s about more than antibiotics that stop working—those resistant microbes end up in nature, where they can actually contribute to climate change and global warming,” say Jeanette and Frank Sams-Dodd.



MPPT acts via capillary evaporation.

if it gets approved, then they’ll reimburse me,” says Negraiff.

While smaller wounds can be healed in as little as one bottle, more complex wounds (including draining fistulas) could require much more and may require lifetime treatment. But for people like Negraiff, Ormsby, and Parry, it’s a small price to pay for the value it provides.

“If you’ve got a pressure sore, which can take months and months to heal, or

even sometimes they don’t heal, definitely use [Amicapsil]. You know, it might cost you a bit of money initially, but in the long run your whole quality of life will improve because you don’t have that infection that you have with the normal dressing,” advises Ormsby.

Another challenge lies in the level of awareness and response to the product among healthcare providers. Amicapsil is not approved for professional use in Can-

ada, so doctors and nurses aren’t allowed to administer it. But in the UK, where it has been approved, some healthcare providers refuse to use it.

“When I first started using Amicapsil, my nurses down at the medical center wouldn’t touch it because I bought it privately. They didn’t want any liability, which was understandable,” says Parry.

Whether it’s concerns about liability, personal beliefs, or a lack of understand-

ing about the product, research shows that it takes time—an average of 17 years—for research evidence supporting a treatment like Amicapsil to make its way into clinical practice.

Advocating For Change

The same challenges existed four years ago when we first reported on Amicapsil in *The Spin*, but there's one important difference: A mounting body of research evidence and a growing number of people who've seen the difference it can make. And with more evidence and more people voicing their support, there's a possibility that healthcare policymakers might see its value too.

While Ormsby has reached out to the Health Secretary of Scotland for support, Parry is petitioning the UK government to make Amicapsil freely available to people with pressure ulcers through the UK's publicly funded healthcare system, the National Health Service (NHS).

"People who haven't suffered from pressure sores, they don't know the full impact," says Parry. "And when you've been a sufferer yourself, and I'm still an ongoing sufferer, I know the impact that pressure sores have on people's lives. And I think if this powder was readily available through the NHS, a lot more people could have a better lifestyle."

While it may take time for healthcare providers and policymakers to come around, the potential for treatments like Amicapsil to transform wound care and enhance the lives of people with SCI is not lost on the Sams-Dodds.

"From the research perspective, this is the first time you've been able to treat an infection in a wound or skin without the need for antimicrobials," says Frank. "And from the clinical and patient perspective, there's a huge unmet medical need in wounds, all types of wounds, not just SCI. And Amicapsil is the first treatment that can close and heal ulcers consistently. The potential to save lives is huge."

Trying It For Yourself

If you'd like to try Amicapsil for yourself, it can be purchased directly from Willingsford Healthcare. To ensure that Amicapsil fits with your other treatments and healthcare concerns, it's a good idea to consult with your medical team first. If your team is reluctant to support it, you always have the option of trying it by yourself. If you move forward with this, Willingsford Healthcare is willing to review daily photos and offer guidance to you, or to your family member or carer who is handling the treatment, via email. For more information, visit willingsford.com or email contact@willingsford.com.

And if you decide to try Amicapsil, please let us know about your experiences with it so that we, in turn, can let other peers know.

For more information about pressure injuries, check out the Skin Health section of our LivingwithSCI.ca website, and be sure to have our Pressure Injury Prevention wallet card handy. ■

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PeerSAY: Go With The Flow

Peeing while travelling can be more than a wee problem. What do you do if the toilet on the airplane isn't accessible? How can you plan for camping or a long road trip? And how do you do all of this discreetly!? Luckily, our peer staff are creative and flowing with great ideas. Read on to find out!

PETER: Be prepared! For those who do intermittent catheterization, products like Coloplast's Speedi Cath Compact and Hollister's Vap Pro Pocket have reservoirs that allow you to cath in areas that don't have toilets. You can make any catheter with a funnel work if you get extension tubing. But you will need to find a discrete location to go and carry a bag full of pee until you can dump it.

BRANDY: It's tough because not all flights have bathrooms that can be accessed. That's where extension tubing can come in handy. Having a jacket or blanket can provide some privacy and it's important to select clothing that's easy to pull off and on. Really difficult to maneuver skinny jeans in a tight space! I make sure I have hand sanitizer or wet wipes, since washing facilities likely aren't accessible if the toilet isn't. Also, anytime you change your usual bladder management system you can have problems like infections. People often don't drink enough when travelling since they worry about toileting issues. When I travel internationally, I use a foley catheter and get prescription antibiotics in advance. For more travel tips, check out: sci-bc.ca/know-how-youll-go.

JOCELYN: Adaptive clothing with a zipper in the inseam is another option. Some hiking pants, like the Gnara Go There Pants, let you unzip and pee. If you're worried about leaks, wearing an absorbent pad can provide peace of mind. One product I've heard about recently is the TravelJohn, or disposable urine bag. The bag contains a substance that instantly turns urine (or any liquid) into a gel, which prevents leaks until you can dispose of it. I might order some and try it out myself.

OLIVIA: That's a cool idea. But it would be hard for us with lack of hand function to hold a bag like that. I actually use an 800 mL blender bottle. It's got a handle that makes it easy to loop your finger through. Make sure you screw the lid on properly, so it doesn't leak.

RYAN: Pre- and post-injury I always trusted the wide mouth 20 oz Gatorade bottle for road trips and camping. When I do the travel presentation here at GF Strong, I tell peers to take an empty one on the plane if they need to tap their leg bag.

TYLER: Like Ryan said, Gatorade bottles are great. They are wide enough to stay between my knees without hanging onto it, don't crumple near the opening, and they don't leak. The bathroom is the reason I haul around a backpack full time. Screw the lid on the bottle and throw it in the backpack to be dumped later. Another hack is to use the catheter covering to add some length to reach the toilet if you don't have extension tubing. Carefully remove the cath from the packaging and place the end of the catheter into the opposite end of the packaging. It could even work in the car—you can park and sit side saddle with the door open.



Gatorade: The unofficial travel drink container for people with SCI

BOTOX: FOR YOUR BLADDER TOO!

One treatment option for neurogenic bladder is Botox injections to relax the bladder. And (like we discussed in "Autonomic Dysreflexia: Botox to the Rescue" in the Summer 2016 issue of *The Spin*) for people with injuries at or above T6, bladder Botox may also reduce the frequency and severity of autonomic dysreflexia.

Typically, the Botox itself is covered by extended health insurance, but not the cost of the needle. But some clinics will now cover the cost of the needle. At the Brenda & David McLean Integrated Spine Clinic (located in the Blusson Spinal Cord Centre) and the UBC Hospital Bladder Care Centre, the cost of the needle will be covered if the urologist determines that bladder Botox is an appropriate option for you.

Participate in Research

SCI research is about much more than test tubes, stem cells, and a far-off cure.

At ICORD (International Collaboration On Repair Discoveries), SCI research is also about improving bladder, bowel, and cardiovascular health; taming pain and autonomic dysreflexia; enhancing sexual health and fertility; new assistive technologies; wheelchair design and ergonomics; and much more. In other words, it's about maximizing recovery, independence, health, and quality of life. But it doesn't happen without you. That's why SCI BC and ICORD are partnering to help raise awareness and increase participation in world-leading research. Working together, we can make SCI research more meaningful and move it along at a faster pace, and we invite you to be a part of it.

Sleep Routines and Sleep Disturbances After SCI

Overview: ICORD researcher Dr. Victoria Claydon, her SFU research team, and community partner SCI BC are interested in learning more about the sleep routines, disturbances, and barriers to sleep supports experienced by individuals with SCI, as well as the impacts of these sleep problems on daily life.

What to expect: This survey study aims to characterize the milieu of routine and physiological sleep disturbances after SCI. The survey asks about sleep quality, sleep routines (i.e., turning), and sleep problems (i.e., sleep apnea) as they present in the nighttime. We will also ask how your sleep affects your quality of life. This online survey is estimated to take 30-45 minutes to complete. You will only be shown questions for the sleep disturbances that you indicate.

Who can participate: You may be eligible to participate in this study if you have an SCI (inclusive of all injury levels, severity, duration, and cause), are living in Canada, are at least 19 years old, and are able to communicate and understand instructions in English.

Why participate: Poor sleep quality is widely documented among individuals with SCI, with consequences of excessive daytime sleepiness, high levels of fatigue, and reduced participation. With the support of patient and community partners, we hope that the results of this study will shed light on the under-recognized challenges of sleep post-SCI to provide context for meaningful change and inform clinical priorities. As a thank you for your time, participants will receive \$15 via e-transfer. At the conclusion of the survey, participants who wish to receive the honoraria will be linked to an external survey to enter an email to which the e-transfer will be sent. Your email will not be linked to your survey responses.

Location: This survey study will take place remotely (online survey/phone).

For more information or to sign up: Please contact the study coordinator Rebekah Lee by email (rebekah_lee@sfu.ca) or call 778-892-8560. You can also go straight to the survey at surveymonkey.ca/r/SleepAfterSCI.

Priorities for Recovery Following SCI

Overview: ICORD researchers in Dr. Andrei Krassioukov's lab are inviting individuals living with SCI, healthcare professionals/clinicians, and researchers/scientists to complete a survey. The goal is to assess the SCI community's priorities for recovery as well as to assess the understanding of recently developed technologies, in particular, spinal cord stimulation as a rehabilitation strategy. This survey will be released internationally to 18 countries to allow for cross-country comparisons and will also include comparisons between the opinions of individuals with lived experience, researchers, and clinicians.

What to expect: This study requires completion of one online survey. It will take approximately 15-20 minutes to complete and will be anonymous.

Who can participate: To participate in this study, you must be aged 18 years or older, able to provide consent and answer questionnaires, and part of one of the following demographics:

- A person with a spinal cord injury.
- A scientist/researcher who is currently doing or has done research involving spinal cord injuries.
- A clinician/health care professional who is currently/previously working in treating/addressing spinal cord injuries.

Why participate: This study will improve education and awareness about what people with SCI need and which health complications are most important for quality of life. The results of the study will be used to guide and improve treatment options/rehabilitation strategies and future research to better align with peoples' priorities for recovery following SCI.

Location: Online survey (links to the survey are provided on the ICORD website at icord.org/studies/2023/09/priorities).

For more information or to sign up: Please contact the study coordinator, Claire Shackleton, by email (shackleton@icord.org) or call 604-675-8816.



Learn more about what makes ICORD one of the biggest and best SCI research centres in the world, and the research they are doing, by visiting www.icord.org/research/participate-in-a-study

Goal-Getters

Build confidence and achieve your health-related goals with SCI BC's new Peer Health Coaching Program.

When SCI peers, researchers, and clinicians all agree on something, that something is probably important. And that is exactly how SCI BC's recently launched Peer Health Coaching program came about.

If you've been an SCI BC member for a while, you may have participated in a research study where you worked with a peer coach. Six years ago, Teri Thorson, SCI BC's Manager of Peer Coaching and Outreach, had her first encounter with peer coaching as part of the University of Toronto SCI & U study. "They were recruiting potential coaches for this study that I ended up becoming a part of," she says. Since that first study, Thorson has been involved with other peer health coaching research projects personally and through SCI BC.

The Proactive study, a similar project with SCI BC, focused on helping people with SCI who were recently discharged from GF Strong or outpatients, meet the SCI physical activity guidelines. "It had such great success that the physiotherapists [who were part of the study] wanted to continue referring their clients to us for coaching after the research study concluded," Thorson explains, "Having people with lived experience as coaches is valuable." Peer coaches understand what daily life with a physical disability looks like and how factors like medication, time spent sitting, and access to recreation opportunities can impact health. And that's the conclusion several research studies came to: Peer health coaching is effective and enjoyed by people with SCI.

So how is peer coaching different from peer support? According to Thorson, coaching is just a different form of peer



Teri Thorson

support. "I really value peer support, like our coffee groups and peer events. It's great to share information and experiences. But I'm a very action-oriented person. So, what I really like about coaching is you work on longer term goals and make plans to action these goals."

SCI BC's Peer Health Coaching program has all the components you need to succeed. After completing a brief intake with Thorson, you will have an introductory meeting with your coach where you will discuss your goals. Thorson adds, "Someone may come in with a lofty goal, but we break it down into bite-sized pieces. We work with where the participant is at, help them gain confidence, and let them lead the way." You will then have eight, one-on-one coaching sessions, up to an hour long, where your coach will help you develop weekly or monthly individualized action plans, find information and resources, check in on your progress, and cheer you on! You choose how often you meet and the delivery method, by phone or video conference.

You can trust that the coaches are ready to support you. In addition to their lived experience, each coach receives training in motivational interviewing

and brief action planning. "I love coaching peers! What an amazing group of people, dealing with such challenging situations after the big adjustments of an SCI. It brings me great joy and gratitude to pass on any insights or knowledge gained after 20 years of living with quadriplegia," shares SCI BC Health Coach Mary Jo Fetterly. Fetterly along with Barry Arana and Olivia Rey, are the three SCI BC staff dedicated to peer health coaching.

"We can help you with any health goal! Increasing physical activity and weight management are common goals, but we can also work on things like improving mental wellness, enhancing strength for transfers, and increasing social engagement," explains Thorson. Regardless of your specific goal, the coaches' aim is to give you the tools and support you need for enhanced health and quality of life.

Don't just take our word for it. Here's what one SCI peer has to say about the program: "After only a handful of sessions, I feel like I've known my coach for years. Their guidance and positive attitude have allowed me to develop skills I probably wouldn't have otherwise. They have given me the hope I needed to visualize a bright future living with my injury."

The SCI BC Peer Health Coaching program is available to anyone in BC with an SCI or related disability, regardless of your age, location, mobility, or time since injury. If you have a goal, we can help you! All coaching sessions are done virtually or by phone. Head to sci-bc.ca/peer-health-coaching-program to learn more about the program and fill out the referral form. ■





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