The State of Michigan legalized medical cannabis (also called “medical marijuana”) in 2009. Many people with spinal cord injury (SCI) have questions about it and wonder if using it may help them. This article provides some general information on medical cannabis and then answers specific questions related to its use by people with SCI.

1. What is cannabis?
Cannabis is a flowering hemp plant. There are three different plant varieties: cannabis sativa, cannabis indica, and cannabis ruderalis. The drug cannabis comes from various strains of cannabis sativa or cannabis indica, or hybrids of both. While marijuana usually refers to the mixture of dried leaves and other dried parts of the plant, hashish refers either to preparations derived from the resin of the plant or to solvent extracts, which are highly concentrated.

Cannabis plants contain hundreds of substances, and at least 60 of them are known to contribute to the sensory, perceptual, emotional, and behavioral effects of cannabis. These active ingredients are called “cannabinoids”. The most widely known and one of the most psychoactive of these cannabinoids is tetrahydrocannabinol, or THC, identified in the 1960s. Plants can vary extremely in their THC content. For example, illegally purchased marijuana in the 1960s had a THC content of 2 to 3%, while today’s cannabis strains contain up to 25%. The other compound found in cannabis that is often monitored and used therapeutically is cannabidiol (CBD), which does not appear to have the psychoactive effects of THC and may have additional medicinal properties.

2. How do cannabinoids and medical marijuana work?
Since the 1960s, our understanding of cannabionoids has come a long way. We now know that cannabinoids can attach themselves, or “bind,” to specialized locations on the body’s nerve cells, activating biological processes. These binding sites are called cannabinoid receptors and they are present throughout the brain, the spinal cord, and the immune system of humans. Research is currently in progress to determine their role in our daily physical and emotional functioning.

Our bodies make their own cannabinoids (called endocannabinoids) which can activate, alter, or shut off these receptors. Scientists have evidence that cannabinoid receptor systems play important roles in motivation and cognition (e.g., thinking, remembering, and learning/problem-solving). Their physical impact includes immune protection, protection from inflammation, gastrointestinal and metabolic effects, and – probably of largest interest to the SCI community – alteration of pain. Because the spinal cord is part of the pain signaling pathway that lets us take action when we have been injured, neuroscientists are now working to better understand the effects of SCI on the endocannabinoid system.

While the cannabinoid system appears to be very important in our daily functioning,
Director’s Corner

Brazilian Researcher Collaborates with SCIMS Researchers on Bladder and Bowel Study

By: Denise G. Tate, Ph.D., ABBP, FACRM

Dr. Fabiana Faleiros, Professor at the School of Nursing at the University of Ribeirão Preto, São Paulo, Brazil spent approximately three months with researchers at the University of Michigan SCI Model System to develop common methods of assessing bladder and bowel problems after spinal cord injury. During her stay, she worked with Dr. Denise Tate, Co-Director of SCIMS, Marty Forchheimer, Senior Research Associate, and others on the translation of international datasets from English to Brazilian Portuguese. The team of collaborators will be comparing data from persons with SCI in Michigan and São Paulo, Brazil, with respect to methods of management, medical complications, and the impact of these on quality of life. The group is also planning joint presentations on the validity of these datasets at national and international meetings in the near future.

Dr. Faleiros had this to say about her experience: “I’m grateful for this opportunity to work with the SCIMS team. We have several topics of research in common, which made for a smooth adjustment in working with the team. I’m sure this collaboration will promote many comparative studies on the rehabilitation of people with SCI in Brazil and the USA”.

Dr. Tate Added: “It has been a great pleasure to host such an accomplished researcher for the past few months. We all have learned a lot about how rehabilitation can influence the lives of persons with SCI in two different countries, based on their needs, aspirations, cultures, and values.”

From the Editor

By: Rebecca Parten, LLMSW

Hello! I am thrilled to be serving as the Editor for this issue of SCI Access. After serving as a consultant last summer, I’m excited to be back with the team. I worked with Maggie Travin and Rachel Hartwig to set up our social media profiles. When Maggie took a new job at MedRehab, I was asked to help with some of the social media and newsletter activities. It’s exciting because it allows me to explore a variety of interests and skill sets such as social media, advocacy, community organizing, public policy and issues related to disabilities. When I’m not working, I enjoy watching Netflix, going to Applebee’s for trivia nights and anything Disney related.

In this issue we cover a variety of different types of alternative “therapies” such as the importance of understanding how your nutritional choices may affect your health, therapeutic massage for pain relief, acupuncture, and meditation. We’ve got something for everyone! We also spent some time getting to know Emily Blauw and Vanessa Lavin for our “Real Life Story” and “Alumni News” articles.

We’d love to hear your thoughts about these articles and suggestions for future newsletter topics! Please send a message to SCI-model-system@umich.edu or call us at 734-763-0971.

New Faces:

Kristin Aho

By: Kristin Aho

Hi! My name is Kristin, and I am a new research technician and dissemination coordinator for SCIMS. I am delighted to have the opportunity to work for the University of Michigan, and I feel that my knowledge and experiences will lend themselves well to our research. I graduated from Oakland University last spring with a Masters in Experimental Psychology, and I am currently working on a Masters at Wayne State in Industrial and Organizational psychology to advance my training in psychometrics and broaden my career opportunities. I previously worked as a crisis counselor and research assistant for Macomb County Community Mental Health. Some past research areas that I have experience with are: female sexual function, suicide, anxiety and sleep disorders, emotion regulation, mindfulness, risky sexual behavior, alcohol misuse, and sexual assault. I do not have prior research experience with spinal cord injury or physical disabilities, but I am enjoying learning about the daily lives of people with SCI as well as the research that goes along with it.

Now that I have all of that academic stuff out of the way, I will tell you some fun things about myself! I’m the artsy farty type, and my newest endeavor is metalsmithing and jewelry design. I am building a studio at home right now and am very excited! I also enjoy long distance running, reading, visiting places in nature like national parks, and anything music or comedy related. During the summer months, you will most likely find me taking a road trip across the country at some point or another.
Medical Marihuana
Continued from page 1

changes to this system can have both positive and negative effects. Current drug development research focuses on how to reduce short- and long-term negative effects, such as decreases in remembering and reasoning, increases in anxiety or depression, losing touch with reality, increased cardiovascular risk and changes in hormone levels.

3. Development of cannabinoid medications
Cannabinoid medicines come in two forms: (1) pharmaceutical substances – cannabis extracts or semi-synthetic agents – that have been derived from cannabis plants; or (2) cannabinoid-dense botanicals. The pharmaceutical forms, such as dronabinol or nabilone, are prescribed to treat nausea and vomiting associated with chemotherapy, or weight loss in connection with acquired immune deficiency syndrome (AIDS). Other pharmaceuticals are currently under review by the U.S. Food and Drug Administration.

People with SCI usually receive cannabinoid medicines in the form of cannabinoid-dense plants that they either grow or purchase at dispensaries. Not only is quality control an issue – dispensed medications may vary a lot in their concentrations of cannabinoids – but dose-response curves, drug-disease effects (particularly when a person has many medical problems), and drug interactions are largely unknown. Thus, administration of cannabinoid medications comes with unknown risks.

4. Routes of administration
Inhaling is the most direct way to get the effects of marijuana. When inhaled, cannabis is quickly absorbed through the lungs and distributed through the blood stream; peak concentrations in the blood are reached within minutes. The effects are generally experienced for 30 minutes – 3 hours, depending upon the amount smoked and the potency. Marijuana is generally eliminated within about 30 hours but complete clearing of the drug from the body is much slower. Sensitive urine tests can detect the presence of metabolites for up to two weeks following a single use.

Smoking the dried flowers and leaves of the cannabinoid botanicals, either as marijuana cigarettes (joints) or through pipes, is both the most common means of administration and the most dangerous. Vaporizing cannabis with heated air can potentially reduce respiratory complications, making an aerosol out of the active ingredients without combustion.

“Edibles” are created by infusing cannabis into butter or oil for cooking or baking. Edibles do not have an effect right away, as smoking does, but the effects tend to last longer, usually 2 – 4 hours, though as with all methods, this depends on both quantity and strength. Dosing is complicated as the drug is absorbed through the gastrointestinal tract and influenced by different metabolic rates, levels of hydration, and prior food consumption.

Marijuana can also be ingested as a tincture, whereby a liquid cannabis extract is made with an alcohol base that can be placed under the tongue or mixed into a beverage. This was the most common route of administration until cannabis was banned in the 1930s.

Finally, medical marijuana can be made into topical applications that can be applied to the skin as lotions, salves, balms, sprays, oils, or creams. These are reported to have therapeutic benefits to symptoms that occur in well-defined areas, such as musculoskeletal pain, restless leg syndrome, some spasms, migraines, and everyday muscle stress and soreness. There is some evidence that this type of administration may protect users from the psychoactive effects of the medication.

5. Drug effects
Marijuana has many effects. If cannabis or any drug - is prescribed for a specific purpose (e.g., pain reduction), all other effects of the drug are termed “side effects.” Some side effects can be more significant than a drug’s intended effect.

Recreational use of marijuana occurs because people seek out the central nervous system effects of THC - the “high” (a sense of euphoria, exhilaration and lack of inhibition) and feeling of being “stoned” (sensations of being relaxed or floating with an altered perception).

Adverse reactions, including temporary psychotic symptoms and paranoia, can occur when using marijuana. Physical effects include flushing (increased blood flow to the skin), increased heart rate, slowed bowel functioning, and increased appetite. As mentioned earlier, use may be associated with increased cardiovascular risk and changes in hormone levels.

Using marijuana may also negatively impact cognition and emotional health. Short-term cognitive side effects can include problems with remembering and problem-solving; it is unclear whether heavy long-term use can cause irreversible cognitive deficits. Also, as previously mentioned, marijuana use has been associated with decreased motivation. In addition, stopping use of marijuana after extended periods of heavy use may result in irritability, sleeping difficulties, anxiety, and boredom.

Cannabinoids can impair psychomotor performance, and its use has been associated with increased likelihood of falls and car crashes. It is against the law in Michigan to drive while under the influence of cannabis. Use among pregnant women is associated with restrictions in growth of the fetus and miscarriages. Also, people with altered metabolism or organ functioning are more likely to experience side effects.

6. What is known about marijuana use in SCI?
As part of a current study by the University of Michigan SCI Model System, we are asking participants with SCI about their marijuana use. Of 242 participants in
the study who answered questions about marijuana use (1 refused), 22% reported using, with all but one reporting using at least monthly. The most commonly listed reasons for using were to relieve pain and spasticity (69% and 46% of users), with recreation mentioned by only 10%. Among the 53 participants who used at least once per month, 26.5% used marijuana more than once per day, 26.5% used it daily, 30% used it 1 to 5 times per week, and the remaining 17% used it 1 to 3 times per month.

Despite its popularity among people with SCI, research evidence on the potential effects of cannabinoids in SCI is limited. Most research has focused on their illegal use. Because alcohol and tobacco often accompany illicit use of marijuana, teasing out the effects of cannabinoids alone is very difficult.

Neuroscience research suggests that SCI disrupts the body’s development of natural cannabinoids. Several clinical studies have looked at the effectiveness of cannabinoids in managing pain among people with SCI. Most studies used survey research, though recently several randomized controlled trials have been conducted. Findings suggest some positive effects on pain, but the relative benefits of cannabinoids in comparison to other pain treatments are unclear. Side effects have varied as a function of how cannabinoids were used. Smoking was used most frequently and was accompanied by dry mouth, constipation, fatigue, and drowsiness. One study noted temporary cognitive problems, particularly among participants using high doses.

Similarly, research on cannabinoids suggests their potential for reducing spasticity. While more research is needed, multiple self-report studies and a few clinical trials conducted among people with SCI have provided some support, as have studies among people with Multiple Sclerosis.

Despite the potential of marijuana in these areas, several of the side effects noted above (in section 5) are of particular concern to people with SCI. Cognitive impairments can limit the ability of people with SCI to keep track of and remember to perform critical health behaviors such as pressure reliefs and cathing, thereby increasing risk of pressure sores, UTIs, and other secondary conditions. Declines in psychomotor functioning can increase existing problems with balance and coordination and further limit the ability to safely conduct transfers or perform activities of daily living. Reduced gastric motility may lead to further slowing in bowel functioning and constipation or impaction. Finally, the same substances in marijuana are useful for reducing nausea and improving appetite in cancer patients can lead to overeating and obesity in individuals with SCI who are already at risk for these issues because of reduced caloric requirements and decreased physical levels of activity.

7. Obtaining a certification card for medical cannabis

On April 4, 2009, the Michigan Medical Marihuana ACT (MMMA) went into effect. It allows individuals with qualifying medical conditions to apply for a license to legally use medical cannabis. The Michigan Medical Marihuana Program (MMMP) is administered by the Michigan Department of Licensing and Regulatory Affairs within the Bureau of Healthcare Services, Health Professions Licensing Division.

The forms and specific requirements for applying for a certification card can be found on the website for the program (http://www.michigan.gov/mmp). Some of the basics include:

- People interested in using medical marijuana must complete and submit an application
- The application must be signed by a physician, confirming the applicant’s diagnosis and the likelihood that medical marijuana may help with symptoms and / or alleviate consequences of their medical condition
- The applicant must pay an initial fee to Michigan Medical Marihuana Program
- After verification of the information in the application, a registry identification card is issued which must be renewed every two years.
- Card holders may carry up to 2.5 ounces of medical cannabis and grow up to 12 cannabis plants for medical use in a locked facility.
- Cardholders can designate a caregiver who (following a criminal background check) can grow and carry the cannabis for them.

Having a registry identification card makes individuals exempt from the laws prohibiting cannabis use in Michigan. Individuals are still subject to federal penalties, including fines or arrests. In addition, Michigan law limits where medical marijuana can be brought or used and it prohibits undertaking any task under the influence, when doing so would constitute negligence or professional malpractice.

Medical marijuana users should be aware that – even with a registry card - their employment may be in jeopardy if their employers prohibit the use of controlled substances while on the job. The MMMA does not require employers to allow cardholders to work while under the influence of medical marijuana and its use is not seen as a reasonable accommodation to be protected under the Americans with Disabilities Act (ADA). As cannabinoids remain in the body at detectable levels for far longer than their effects can be felt, testing positive for cannabinoids may be grounds for termination.

While a large number of dispensaries exist – including over 120 in Detroit and 20 in the Ann Arbor / Ypsilanti area, the MMMA does not contain rules for distribution or sale of medical cannabis. At this time, dispensaries operate in a gray area and may be subject to closure if deemed a “public nuisance” by their communities.
Here in Ann Arbor, MI, the approach that is popular currently involves cooperatives of caregiver-growers who operate dispensaries. Co-ops bring together people from a variety of backgrounds, including horticulturalists to grow relevant strains of cannabis, consultants to provide personalized recommendations to patient-members with differing needs, and lawyers and administrators to ensure adherence to relevant laws and develop relationships with communities. Members of these dispensaries can obtain a wide variety of strains and types of medical cannabis products, including dried leaves, edibles, tinctures, waxes and salves.

8. Responsible use

If you are considering using medical marijuana to deal with symptoms associated with your SCI, it is best to approach the decision in the same way you would approach any other medicine. What are the treatment goals? How will you know that the treatment is working? What are the benefits? What are the risks? Because production is uncontrolled and physicians do not prescribe particular doses of medical cannabis or suggest a certain amount or level that could be therapeutic, it is up to you to keep yourself safe and manage administration, not doing activities such as driving or using heavy equipment.

While we do not and cannot recommend using medical marijuana, if you are going to use it, it will be important to monitor or keep track of:

- what type of medical cannabis you are using (increasingly strains exist with accepted names), where you obtained it, how you are using it, the amount and frequency
- the degree of relief you experience
- unwanted side effects
- other medications you took during the same time frame

Treat drug administration as if you were conducting an experiment with yourself as the subject to determine what works best for you. As pointed out earlier, the potency of medical marijuana varies greatly, and many factors can alter the effects of the drug.

9. Collaborate with your physician

Consult with your physician and ask her or his input, particularly as medical cannabis may interact with some of the medications you are already taking. Because all prescription medications have side effects, ask your physician for information regarding the side effects of medical cannabis as well as your other medications with which it may interact.

Once you have identified a therapeutic amount of medical cannabis to take, maintain that level and track the factors that may influence its effectiveness. If you find that it is helping you, talk to your physician to find out whether you can reduce or discontinue other medications that you are taking for the same problem, such as pain or spasticity.

While UMHS guidelines suggest that clinicians counsel individuals not to substitute medical cannabis for their prescription medications, sometimes individuals with SCI want to try medical cannabis because they are dissatisfied with their current medical regimen. In any case, a discussion of how and why an individual with SCI would like to use medical cannabis is important, so collaborative treatment decisions can be made.

While the MMMA protects physicians from being arrested, prosecuted, or penalized in any manner for discussing marijuana for medical purposes, physicians are not required to support patients’ medical cannabis registration or prescribe medical cannabis. Most will at least provide you with information to help you make informed decisions.

10. Make your drug regimen work for you

As pointed out earlier, any substance strong enough to have benefits also has the potential to cause harm. A good rule of thumb is that medicines and other substances should make you more functional; you should be able to engage in more activities, not fewer. While some medications may cause side effects, they continue to be prescribed or administered because they potentially provide long-term benefits.

When considering whether to use medical marijuana, apply the same standard. Ask, what is known about how it will affect my ability to function in both the short and long terms? Will my patterns of use interfere with key areas of life, including my ability to manage my health, my relationship, and my employment and education?

Individuals who have had substance use disorders in the past, including those resulting from use of prescription medications, may not be appropriate candidates for medical cannabis. Moreover, if a person has had a cognitive disorder in the past, or has heard or seen things that others could not, use of the drug may enhance the risk of this reoccurring.

Good advocacy for yourself involves getting all the facts, applying them to your unique situation, and then weighing risks and benefits, carefully and in collaboration with your providers, to reach a decision.

11. References and Resources

For more details on the MMMA, go to https://www.michigan.gov/mmp or the Michigan Department of Licensing and Regulatory Affairs https://www.michigan.gov/lara/0,4601,7-154-35299_63294_63303_51869---,00.html

For a review of arguments both for and against Medical Marijuana Use: http://medicalmarijuana.procon.org/


University of Michigan Health System (UMHS) Information and Guidelines

- General Information: http://www.uofm-health.org/health-library/abl2153

Disclaimer

This article was written to provide information and generate thought and discussion of this issue. It should not be taken as medical advice or an endorsement of using marijuana for therapeutic or other purposes.
Acupuncture & Spinal Cord Injury

By: Ligia Andrade

Spinal Cord Injury (SCI) is a very complex condition and can have a variety of complications. One of the most common is pain. In the United States, pain relief is often obtained by using narcotics, other medications, and other “traditional” treatment options. In other parts of the world, alternative therapies such as acupuncture are more commonly used. These therapies may provide the same or even more effective pain relief.

Acupuncture is a method used for relieving several kinds of pain, as well as other problems, by inserting very fine needles in different pressure points of the human body.

Acupuncture originated in ancient China but is also practiced in Korea, Japan, Vietnam, and, while less frequently, throughout the world. There are several different forms of acupuncture. The differences depend on the theory, opinion, particular diagnosis or diagnoses, and technique used. For example, Traditional Chinese Acupuncture is the most popular worldwide. This form of acupuncture aims to promote balance in the body and mind, regardless of diagnosis. The theory behind it is that when the physical, mental, emotional, and spiritual realms are balanced, overall well-being is achieved. Japanese or “Classical Acupuncture” focuses on the “Five Element Theory”. It uses less stimulation and fewer, thinner needles. Korean acupuncture uses only 4 needles and is related to “Classical Acupuncture”. Korean Acupuncture focusses on the hand and ear, with the whole body being treated through use of needles in these extremities. In Auricular Acupuncture or Auriculotherapy, the ear is used to treat the rest of the body. Usually, Auriculotherapy is used for pain control and drug, alcohol, and nicotine addiction. Now that acupuncture is becoming popular in the United States, Western doctors use Medical Acupuncture, which focuses on acupressure points, often together with electric stimulation, to relieve and manage pain.

In addition to pain, acupuncture can be used to relieve many different symptoms among people with SCI, including nausea, constipation, anxiety, insomnia, and spasticity. In traditional Chinese medicine, the theory of Acupuncture points (meridians or channels) work together to create a network that aligns the surface of the body with the internal organs. When pain or illness is experienced, it is believed that there is a blockage in the meridians or channels. Acupuncture works by removing the blockage and restoring balance by creating healthy circulation. Because SCI disrupts circulation and affects the nervous system and autonomic systems in the body, acupuncture may help in the realignment of the meridians or channels.

Among people with SCI, the most popular use of Acupuncture has been to relieve and manage pain and spasticity. In 2013, a patient named Denise acquired a C4-C7 spinal cord injury after having surgery to treat a vascular malformation. About a year and a half later, she decided to try acupuncture after a recommendation from a family friend. Denise did not expect that it would help her but after receiving several treatments she noticed a significant reduction in both the frequency and intensity of her spasticity. Because of Denise’s injury, only one of her arms is functional. The arm that is not functional has caused her a great deal of pain. Acupuncture has also seemingly reduced her pain, giving her an option for pain management without requiring medication. In reducing her pain and spasticity, it seems that acupuncture has allowed Denise to gain more strength and flexibility in both arms. Denise feels that acupuncture has improved her quality of life without resulting in side effects.

Another patient, Kirk, acquired a C6-C7 SCI 30 years ago as a result of a diving accident. He endured many years of chronic pain and his heavy use of pain medications limited him greatly. About three years ago, he started seeing a new medical provider who, after learning that Kirk had severe pain in spite of his taking pain medication, offered him an alternative form of pain management: acupuncture. Because Kirk had experience with other alternative healing methods such as crystals, he was excited to try acupuncture. During his first acupuncture session, small fine needles were inserted on the top of his head as well as in other areas on his body. Unfortunately, he received no relief. Over time, the placement of the needles was changed to pressure points in his ear and this did seem to relieve his pain. Magnets were used along with acupuncture. Small metal tabs were inserted into his ear and he was given small magnets to pass over them. This seemed to provide several days of relief, allowing him to have fewer medical treatments. While the treatments varied in their effectiveness, they allowed him to reduce his use of pain medication. In the beginning, Kirk had not expected acupuncture to help him much. Ultimately, he learned a new way to manage his pain, which seems to have improved his quality of life. Overall, his experience was positive, and he recommends it to others who suffer from chronic pain due to SCI.

The cost of acupuncture varies from provider to provider. While most medical insurances will not pay for it, some may. If you are interested in trying acupuncture, contact your medical insurance provider to find out if they will cover it. Before trying any new form of treatment, it is important to understand it by doing your own research, talking to your health care provider, and, if possible, speaking to others who have experience with it. For Kirk and Denise, acupuncture seems to have provided relief from chronic pain and spasticity. Not appropriately treating these problems can affect quality of life, leading to depression as well as the side effects that can result from being overly medicated. Non-traditional methods of treatment such as acupuncture may be less taxing on your body, which already has to work hard to stay healthy.
A nutritious diet is a critical factor in everybody’s health. There are specific nutritional considerations to maintain healthy functioning of the body after SCI, however. Damage to the spinal cord affects the physiologic function of multiple organs in the body, and diet and nutrition play a role in the health of many of these organ systems as well as preventing metabolic diseases, such as diabetes.

Altered bowel habits such as constipation or incontinence are one common consequence of spinal cord injury. While the neurologic function of the small and large intestines may remain intact after SCI, impaired voluntary control of the pelvic floor muscles to have a bowel movement, decreased physical activity level, and medication side effects may all affect bowel functioning. In particular, healthy bowel function depends on the vast population of normal, healthy bacteria that live within the intestines (the “gut microbiome”). Changes in the normal population of bacteria in the intestines due to antibiotic use have long been recognized as a risk factor for overgrowth of an unhealthy bacteria in the gut. Clostridium difficile (C. diff) can lead to diarrhea or even life-threatening disease. The gut microbiome may play a role in limiting routine functioning of the bowel, leading to problems such as irritable bowel syndrome. It is increasingly recognized that the gut microbiome affects metabolic diseases like obesity, immune system function, and even brain function.

While altered bowel habits and antibiotic use may put people with SCI at increased risk for diseases associated with an abnormal gut microbiome, diet and nutrition can help restore the normal, healthy balance of bacteria in the gut. There are a large variety of probiotic (“healthy bacteria”) supplements commercially available which can affect the gut microbiome. While these probiotic supplements are generally safe to take, there is no consensus on which specific strains of bacteria are the most important or beneficial. Certain foods contain a spectrum of healthy bacteria, including fermented foods such as yogurt, kefir, sauerkraut, sour-dough bread, kombucha tea, and kimchi. Other foods (“prebiotics”) high in specific fiber or starch content can be beneficial in providing fuel for the healthy bacteria in the gut. These include asparagus, onions, whole grains, broccoli, Brussel sprouts and kale. Incorporating these probiotic and prebiotic foods into one’s diet may help maintain healthy bowel functioning and decrease risk of immune system and metabolic diseases.

Nutrition can also play an important role in maintaining bone health after SCI. The hips and lower extremities are especially at risk for loss of bone density and fractures after SCI since the bones are exposed to less weight-bearing force and muscle contraction force. Besides these physical forces, maintenance of healthy bone structure depends on adequate calcium and vitamin D levels in the body. People with SCI tend to have reduced vitamin D levels. While our bodies produce vitamin D naturally in response to sun exposure, it can also be obtained through diet. Vitamin D is stored in fatty tissue, and foods high in vitamin D include fatty fish like salmon or tuna (including canned tuna), egg yolks, cod liver oil or beef liver. Vitamin D is also often artificially added to milk, orange juice and cereal. Vitamin D supplement pills are another way to get adequate intake in one’s diet. Besides bone health, recent research suggests that low vitamin D levels may play a role in many other health problems, including cardiovascular disease, diabetes, high blood pressure, cognitive impairment, and chronic pain.

Decreased physical activity and changes in muscle tissue metabolism after SCI are risk factors for diabetes, a disease which can have many devastating complications. While instituting a physical activity program can be challenging with SCI, especially for those with tetraplegia, diet is more easily controlled and is just as important in preventing diabetes. A healthy pancreas produces insulin in response to carbohydrate intake. In type 2 diabetes (“adult onset”), the pancreas produces more and more insulin in response to carbohydrates, and the body becomes resistant to the action of insulin to reduce blood sugar levels. One then faces the bad effects of hyperglycemia (high blood sugar). Certain foods trigger this disease pathway more than others. Specifically, eating refined or processed carbohydrates like high-fructose corn syrup, sucrose (“table sugar”) and refined wheat (“wheat flour” or “enriched flour”) leads to higher insulin and higher blood sugar levels than eating the same amount of carbohydrates in whole fruits, whole grains, vegetables, beans, nuts, chicken, beef, eggs and fish. These unprocessed foods may contain just as much sugar, such as in a piece of fruit, but the sugar is bound up with fiber that slows down its absorption by the gut and reduces its effect on insulin secretion by the pancreas. Thus, the unprocessed foods are less likely to trigger the pathway leading to hyperglycemia and diabetes. Be aware, and check the labels for refined sugars and refined flour when buying packaged foods.

These recommendations are just a few examples of the importance of diet and nutrition in staying healthy after a spinal cord injury. A well-balanced diet of unprocessed foods lays the groundwork, but talk to your healthcare provider to determine if other supplements or dietary choices might be right for you.
Therapeutic Massage

By: Tom Hoatlin

Therapeutic Massage has emerged as one of the most effective alternative and holistic treatments offered for people with disabilities and chronic health conditions. While it isn’t meant to replace regular medical care, benefits include stress relief, decreased pain and muscle tension, and the deterrence of secondary conditions.

Massage can also improve one’s mental health. A 2002 University of Miami study assessed the effects of massage therapy on depression, functionality, upper body muscle strength and range of motion in patients with SCI. Twenty individuals with cervical SCI participated. They were randomly assigned to either massage therapy or an exercise group for five weeks. Although members of both groups appeared to benefit from treatment, only the massage group showed lower anxiety and depression scores and significantly increased their muscle strength and wrist range of motion. (Diego MA, et al. Spinal Cord Patients Benefit from Massage Therapy. International Journal of Neuroscience. 2002;112:133-142.)

Chad Lawson, a certified massage therapist, has worked at Strength Training and Recovery – Star Rehab, in Grand Blanc for seven years. He specializes in working with people with SCI and/or amputations. Chad reports that because his clients have compromised sensation and motor function, his treatments are highly individual, catering to their specific requests. For instance, some only like to concentrate on the areas of their body where they have sensation. Others want a full body massage. Chad shared that the reason for this is that all injuries and needs are different. For example, even though his clients may not be able to feel their legs, they might choose to have them massaged to decrease spasticity and increase circulation.

While there are many types of massage therapy, people with disabilities often ask for Deep Tissue or Cranial Sacral massage. While the benefits are similar, the differences in application are vast. Deep Tissue massage is aimed at the deeper tissue structures of the muscle and fascia, or connective tissue. It uses many of the same techniques as a Swedish massage, but the pressure is more intense. It is also more focused, as the therapist works to release chronic muscle tension or knots, also known as adhesions. Cranial Sacral therapy (also known as craniosacral therapy) is a gentle, noninvasive method of body work that addresses the bones of the head, spinal column and sacrum. The therapist works to release compression in these areas, which decreases stress and pain. Cranial Sacral therapy works to restore the natural positioning of the bones and helps to decrease symptoms from chronic injuries and provide relief from migraine headaches, neck and back pain.

Ann Manning, a person with incomplete quadriplegia, is a regular client of Chad’s. “For me, a good massage is amazing for stress, pain, and spasm management. I experience improved gait and posture, decreased spasticity and pain, and a feeling of total relaxation.”

If you haven’t tried massage therapy, put aside any thoughts of it simply serving as a way to indulge or pamper yourself. Massage can be an integral and powerful tool to help take charge of your health and well-being. Doug Edmunson is another regular client of Chad’s who’s had a T-11 complete SCI for eight years due to an auto accident. He says, “Through multiple years of different therapies, massage therapy has been a huge benefit in my life and recovery. I don’t take medication for muscle spasms, this is a choice I battle with every day, but massage therapy has made my decision a lot easier. After a session of massage therapy, my body is more relaxed from less muscle spasms and pain levels are down for hours after. This makes everything in life a little easier to handle and I have more energy to use throughout the day. Massage therapy plays a major role in my quality of life.”

-Doug Edmunson

Here are some important things to remember when considering therapeutic massage:

- Consult with your doctor first and follow any treatment recommendations they make.
- Communicate with potential massage therapists about your unique condition and ask important questions such as: Are you licensed? What is your experience level with patients in general and those with SCI? How many sessions would you recommend considering my goals? What is the cost and is it covered by my insurance?
- If any part of your therapy does not feel right or is painful, speak up. Too much pressure can result in serious injuries.

No matter what kind of massage you choose, you should feel calm and relaxed during and after your therapy.
Aromatherapy

By: Wendy Mauntel, BS, RRT, ND

Aromatherapy utilizes essential oils extracted from roots, leaves, seeds or blossoms of plants to balance, harmonize, and promote the health of the body, mind, and spirit. Essential oils have been used for therapeutic purposes for thousands of years. The ancient Egyptians, Greeks, and Romans used them in cosmetics and perfumes. They were also commonly used for spiritual and ritual purposes.

In 1910, a French chemist, René-Maurice Gattefossé, discovered the healing power of essential oils when he applied lavender oil to a burn on his hand caused by an explosion in his laboratory. He then began to analyze the chemical properties of essential oils and began to treat burns, skin infections, and even wounds during World War I. By the 1950s massage therapists, and other complimentary healing practitioners started to incorporate essential oils into their healing modalities.

It is believed that inhaling essential oils stimulates the part of the brain connected to smell and then a signal is sent to the part of the brain that controls emotions and memory. This causes chemicals to be released which make the person feel relaxed, calm, or stimulated depending on which essential oils are used.

The complimentary nature of aromatherapy has been growing in popularity in the United States and is used in a wide range of settings—from health spas to hospitals—to treat a variety of conditions. One of the most commonly used essential oils is lavender. It has been used to promote a sense of relaxation as well as relieve anxiety, stress, insomnia, and depression. Another promising essential oil is peppermint, which is used to treat headaches, nausea, and upper gastrointestinal cramps.

Finally, when using any type of complimentary therapy, it is wise to consult your physician, as each individual has specific needs and concerns.

To learn more about aromatherapy you can contact Wendy through The Training Institute for Vibrational Medicine www.MerkaMed.com, 810-772-1990 or info@wendymauntel.com.

ReWalk™ Robotics Lecture Success

By: Kristin Aho

The University of Michigan SCI Model System hosted a Rewalk™ Robotics lecture on June 2, and it was a success! The ReWalk™ exoskeleton is an ambulation alternative for wheelchair users, enabling people with lower limb disabilities, such as paraplegia, to stand and walk. Christine Wallis, a therapist at The University of Michigan’s MedRehab Briarwood site, led the discussion about the new technology. The lecture covered the history of assistive devices for ambulation, the development and use of ReWalk™, the training program at MedRehab, differences between the rehabilitation and at-home versions of the device, and future directions. We were also pleased to have Craig Peters, a representative from ReWalk™, join us. He was able to answer more technical questions related to insurance coverage and future ReWalk™ developments. In addition to Christine’s presentation, two individuals demonstrated how to use the ReWalk™. Mike (see photo), a patient from MedRehab in Ann Arbor, and Dan, a patient from MossRehab in Philadelphia, demonstrated how to use the device. They also discussed their experiences in learning to use the device as well as how the ReWalk™ has benefitted them personally. Some of the benefits that our ReWalkers feel they have gained from using the ReWalk™ include better weight management, putting weight on the bones in their legs, increasing muscle definition, and being able to stand up and talk to people face-to-face. If you were unable to attend the lecture, don’t worry! We will upload the video to our YouTube channel (UM-SCIMS Lectures) as soon as it is ready. If you are interested in being evaluated as a candidate for ReWalk™, please contact MedRehab Briarwood at (734) 998-7888. More information is also available at www.rewalk.com.
Meditation is showing up in more and more places these days, from corporate stress reduction programs at companies like Google and Procter & Gamble, to wellness and heart disease prevention classes, and even among athletic teams. The appeal is that meditation does so many positive things. It’s a tool that allows you to become calm on demand and to better cope with life’s challenges. It has been shown to have many health benefits, such as reducing blood pressure, pain, and inflammation as well as boosting the immune system. It is also used to enhance performance. People find meditation helps with focusing ability and boosting creativity.

While many therapies, traditional or alternative, require a clinician to administer them, meditation is one practice that you can learn to do independently with no props or special equipment needed. The essence of the practice is to shift your attention from the external world and the jumble of thoughts, opinions, and judgments that usually crowd the mind to intentionally slowing down and focusing on one thing, something neutral or positive. With relatively little experience, you can learn to stop, close your eyes, and bring attention to your breath (or some other aspect of your inner experience), and just let go of everything else.

This shift to inner awareness brings about deep relaxation. It slows down the heart and respiration rate as well as releases muscle tension. It also reveals the ways you often increase your stress by the way you habitually react to circumstances. By becoming quiet and noticing what goes on when you try to focus on your breath, you create a little peek into what may be going on all the time. You may observe yourself getting frustrated with your lack of concentration, disturbed by thoughts of an argument you recently had with a loved one, or anxious about something looming in the future. Meditation encourages you to pay attention, notice the pattern, let go of distractions, and return to the present moment. The carryover into your daily life is that you may notice that same pattern of thinking as it arises and more deliberately choose a better response.

There are several different styles of meditation. Concentration meditation involves keeping attention on your breath or a mantra, word, or sound. Mindfulness meditation entails staying present in the moment and accepting whatever arises without judgment. Contemplative meditation uses imagery or directed thoughts and feelings, such as appreciation or loving-kindness as the object. These all serve to relax the body and train the mind. In the same way that physical conditioning takes some effort and discipline, so does meditation. It works best when it is done routinely so that it becomes a habit. The most common obstacle people mention is a belief that they are not doing it right because they cannot concentrate or have too many thoughts. However, that is normal and part of the experience. With practice it becomes easier to stay calm and present, even in the midst of thoughts.

The best way to get started is to take a class. It can be helpful to have a teacher’s personalized instruction and the structure in place to better establish a regular practice. “Learning to pause, not just during chaos, but beforehand, really helps my mood stability throughout the day,” observes Claire, a student at the end of a six week meditation course. “I have become much more aware of things going on around me and how I react to them.” There are plenty of resources online (see below). With all the stress these days and the noise and stimulation of electronic gadgets, this ancient practice of sitting quietly with presence could be just the thing to restore some peace into our lives.

**Resources**

- UCLA Mindfulness Resource Center: http://marc.ucla.edu/body.cfm?id=22
- Chopra Center: http://www.chopra.com/ccl/sections/meditation
- Headspace Meditation App: www.headspace.com
- Stop, Breathe and Think: http://stopbreathethink.org/

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**Just Sit Still: Meditation for Health and Well-being**

*By: Sandra Finkel, M.P.H. (finkelsand@gmail.com)*

Sandra Finkel, M.P.H.
Research Studies Currently Being Conducted by the U-M Spinal Cord Injury Model System

By: Martin Forchheimer

Site-specific Study 1: Bladder and Bowel Complications and their Impact on Quality of Life after SCI:

This study examines the nature of bowel and bladder management and the relationship of these, personal characteristics, and other factors to bladder and bowel complications and ultimately to quality of life (QOL). We have collected data from almost 300 people with SCI so far who have been living with their injuries for at least 5 years. While we have not completed data collection yet, we have done several presentations at conferences about the development of the study and preliminary findings. To conduct this study, we had to develop a few new questionnaires, including the Bowel and Bladder Treatment Index or BBTI. The BBTI includes a detailed assessment of the methods used, complications experienced, and the impact of bowel and bladder management and complications on life. Several groups in the US, Brazil, and China are now planning to use the BBTI for their research. As a result, we may be able to evaluate data about bowel and bladder health and management from a much larger international sample in the future than we could study here at U-M.

Site-specific Study 2: Bowel and Bladder Complications after SCI in Daily Life:

A group of the participants in Site-specific Study 1 are participating in this study, which is an in-depth study that looks at the impact of bladder and bowel issues on daily life. Participants track events that are notable for seven consecutive days.

Site-specific Study 3: Applying Health Mechanics to Enhance Bowel and Bladder Health for Persons with Spinal Cord Injury:

This study evaluates the efficacy of the Health Mechanics self-management program to improve bowel and bladder health among people with SCI living in the community. This study is a randomized clinical trial. All participants complete a series of 4 surveys over the course of one year. Approximately half are randomly selected to also receive a telephone-based intervention, which contains 6 sessions. Those who do not receive the intervention are also given access to written information about health management after they have completed the study’s surveys. We are still actively recruiting subjects for this study. To qualify, participants must have experienced a traumatic SCI at least six months before joining, have some changes in their bowel and bladder functioning due to the SCI, be living in the community (not in a sub-acute facility), and be interested in participating in the intervention if selected. If you or someone you know may be interested in participating, please contact Brad Trumpower, at: (734) 764-5217 or via e-mail at: trumpb@umich.edu

Multi-Center Study 1: Evaluating the sensitivity and responsiveness of the SCI-QOL CATs:

The SCI-QOL was developed as part of an earlier study that was funded by the National Institutes of Health. It measures QOL in various areas, including physical activity, medical issues, emotional well-being, and social participation. Computerized adaptive tests (CATs) determine what question respondents should be asked based on their responses to earlier questions. This allows scores to be obtained with a small set of questions that are similar to those that would be obtained from asking a much larger number. As part of the current Model Systems grant, a number of participating centers have been using the SCI-QOL to determine its sensitivity to change over time as well as other aspects of its usefulness. U-M has been participating in the SCI-QOL project since its initial development. Some of our participants took part in the initial focus groups as well throughout the measure’s development and testing process. This May, a special issue of the Journal of Spinal Cord Medicine was dedicated to articles about the SCI-QOL. Although these articles were written primarily for an audience of researchers and clinicians, some may be of interest to people with varying backgrounds. The listing of articles, their full texts, and summaries of the articles (called citations on the website) can be viewed on-line at: http://www.maneyonline.com/toc/scm/38/3. If you do not have access to the internet and would like information about these articles, please contact us at: 734-763-0971.

Multi-Center Study 2: Enhancing and Evaluating the SCI-FI:

The SCI-FI is similar to the SCI-CAT in that it is a system to evaluate the status of people with SCI using CATs. It focuses on functional well-being in the areas of Ambulation, Basic Mobility, Fine Motor Function, Self-Care, and Wheelchair Mobility. The SCI-FI was developed by a group of SCI Model Systems, including U-M, between 2006 and 2011. During the current funding period, these Model Systems have modified the SCI-FI to take into account the use of assistive technology, and are now evaluating how respondents’ scores change over time.
Everyone has their own story to tell, a unique set of experiences and endeavors that have helped shape us into the individuals we are today. In a rehab hospital, every patient has a unique story. There are stories of life before and after injury, times they felt discouraged and times they felt inspired. As a newly admitted 16-year old SCI patient in a rehab hospital, I struggled with feelings of pain, anger, and loss from the unwelcomed disruption my injury had caused to my life. However, as I began to participate in therapy, I took interest in the stories of other patients; stories of recovery and rehabilitation into a new life, and how they adjusted to a new normal. These stories gave me the courage to focus on my own journey to recovery. Through the healing process of therapy, I became physically and mentally stronger. I began to navigate life and the world around me in a way I had never thought possible. This is a glimpse of my story, a story of tragedy and hope that brought me from living my own rehab to working in rehab.

On February 14, 2001 I had been with my elite choir doing “singing valentines” all day in our ball gowns and tuxedos. I was just sixteen years old. We met back at the school that evening for pizza, before we headed home for the night. It was one of those typical February West Michigan days with a mixture of lake effect freezing rain, snow, and slush coming down and covering the roads. When I headed home I realized how bad the weather was. Despite taking it slow, just a few miles from my house my car suddenly hit a patch of black ice, slid, spun to the side, and slammed into a tree. I held on to the steering wheel so tightly that, later on when I asked what the dark bruises were in my hands, they told paramedic heading home on a different route then he normally takes. He came to my aid immediately and protected me from additional harm while waiting for emergency services to arrive. He called for an ambulance and helicopter because he knew it was serious. My parents arrived as emergency crews used the jaws-of-life to open my car to get me out on a backboard and put me in an ambulance and then to the nearby helicopter. After the helicopter landed at Grand Rapids Spectrum Health downtown, I was rushed to the emergency room and the on-call chaplain was called. It was my grandfather, a volunteer chaplain who worked one day a month. He was able to be with me and support my parents when they arrived at the hospital after traveling from Holland.

My head and neck were put into traction with a halo. Not the angelic kind; the kind that has four screws that go into your skull and attaches to a solid turtle shell vest. The next day, my vertebrae were fused in surgery, using part of my hip bone to rebuild the shattered vertebrae from C4-C7 and held together with titanium rods in my neck. I woke up in the ICU with the halo, G-tube, Chest tube, and a tracheostomy attached to the ventilator. After 14 days, I was stable and alert so I was transferred to Mary Free Bed Rehabilitation Hospital. It was like boot camp. At that point it became clear to me that the real work was about to begin. The little things were difficult when
rehab began. My body was weak from atrophy. With the tracheostomy I never felt like I was getting enough air. I was 5'8" and my weight dropped down to 90 pounds. One of the most difficult tasks to overcome was the orthostatic hypotension. My blood pressure dropped drastically low whenever I was moved into an upright position. I had to fight not to pass out daily. Even just trying to sit up in a straight back wheelchair for 15 minutes was difficult. After a long day in numerous types of therapies, I still had high school homework to do so I didn’t fall behind too much in my junior year. Sometimes I hated my therapists for pushing me when I felt so sick and weak, but now I realize how much they wanted me to be independent and successful.

Following almost 5 months of inpatient rehab, I was discharged and headed home to start up with outpatient therapies. At that time, I returned for my senior year in high school. While most of my peers were thinking about going to a college or getting into a trade, I was learning how to write again and navigate crowded high school hallways in a wheelchair. However, I too was thinking about college: if I could do it, what would I be interested in, and what would I be good at. Taking all of my interests and my own rehab experiences into consideration I decided that speech-language pathology was the career for me.

I set my goals high, and I graduated with a B.A. from Hope College then went on to earn my graduate degree and M.A. Certificate of Clinical Competence for Speech-Language Pathologists (CCC-SLP) from Western Michigan University. Classes were tough but good, and clinic proved to be challenging because I had to figure out different ways of doing things in my chair. For example, I had to learn how to catch a two year old “runner”, or how to manipulate items such as data collection tools or documentation with my “quad-hands”. I learned quickly that I could use my chair as an advantage with some of the little ones. The wild ones that wanted to run can be easily trapped in a corner with my chair on an angle. Some children don’t want to go to therapy, but if you give them a job (i.e. helping to push my chair to the therapy room) they’ll feel important and participate. Kids always ask the best questions about my disability, and that meets some of their language use needs.

I found my niche in outpatient therapy. I have worked at Mary Free Bed outpatient center in Grand Rapids for five years and am on the pediatric and adult neuro teams. I now work in the same rehabilitation center where I was a patient years ago. I work closely with some therapists who were my therapists. I enjoy working in outpatient therapy because I can build meaningful relationships with my patients as I help them rehabilitate into a functional world. I often joke with them saying this is their speech therapy but my own OT, as I practice quicker hand function with the cards, timers, etc.

It takes a lot of hard work to balance and manage a life and full-time career while having limitations and needs for some of my own physical care. I take a proactive approach with my medical care. I routinely get up at 5am to start my day with medication, a bowel program, shower, and prepare the catheters that I will need throughout the day. Everything takes a little longer, and I have a caregiver in the early hours of the morning so I can get out the door on time. I run a tight ship to get everything done and off to work to see my patients as early as 8 or 9am. There are extra considerations I need to be aware of throughout the day like maintaining regular pressure reliefs and a regular cathing schedule as well as monitoring my blood pressure between patients throughout a very busy day.

As a therapist, I strive to offer compassion and hope to all of my patients and that little bit of tough love to push them through the hard times. I do this to increase their independence and quality of life in finding their new normal. I hope that I offer my patients some comfort in knowing that I know what it’s like to have a debilitating injury and, despite some permanent, visible/invisible scars, they too can overcome them and find meaning and purpose in life. I do not sugar coat things and I am honest with my patients even so much as to bluntly state that sometimes “this sucks”.

In 2010, I was named Miss Wheelchair Michigan and created a platform To Empower Children with Disabilities. I assisted Mary Free Bed in forming a scholarship for persons with disabilities who are entering a career in rehab and was appointed by the governor to serve on The Barrier Free Design Board for the state of Michigan. I continue to serve on the state board and recently founded the Universal Design Committee at Mary Free Bed Rehabilitation Hospital.

One of my favorite quotes is from Nelson Mandela: “The greatest glory in living lies not in never falling, but in rising every time we fall.” We all have falls. We all have our own stories, our own disabilities, and our own struggles to overcome. We all struggle to get back up again. No one’s life is without imperfection, but you can stand back up, make a choice to push ahead, and persevere to enjoy life in all circumstances. Always be an example of positivity in the daily ups and downs, because they will happen. There is power in taking ownership of your own healing. Listen and relate to others through their stories and life experiences, and they will inspire you too.
Alumni News: Vanessa Levin

By: Constance Pines, RN

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We enjoy hearing from our Alumni! The SCI Access Newsletter would like to include news and advice from you, our alumni, in future newsletters. It is important to us to highlight your experiences and triumphs and look forward to hearing from you. You may contact us online at our website www.med.umich.edu/pmr/modelsci or call our office at 734-763-0971 for information.

Alumni News: Vanessa Lavin

Name: Vanessa Lavin
Age: 46
Date of Injury: June 1st, 2013
Level of Injury: C2

SCI Access: Tell us about yourself! Have any significant events taken place since your injury? Do you have any hobbies? What have you accomplished? What do you do for work?

VL: I am a mother of a fourteen year old and an eleven year old, so that in itself is an everyday challenge. Learning to manage my own care as well as theirs has been a tremendous learning experience for all of us. Being a quadriplegic is proving to be a lot of work. I am pretty high maintenance, which I’ve learned. Humor is something that gets me through each and every day.

Before my accident, I was extremely physical, using my body to its fullest. I was a personal trainer and group fitness instructor. I was involved in my children’s sports and activities by coaching and mentoring. I was also an artist, having had several successful exhibits. Now, I occasionally teach yoga classes as well as spin classes. I have also started back into my art with drawings and paintings.

SCI Access: Briefly tell us about your injury experience. What were some challenges, positive/negative experiences, etc.?

VL: I acquired my injury on a beautiful spring day. I wish that I could say it happened because of some exciting experience like sky diving or bungee jumping but I cannot. I was doing a simple and mundane activity. We were putting the boats in for the beginning of summer and I simply fell while trying to put the canvas covering over the boat. How I lost my grip, who knows? All I know is that the fall and subsequent hitting of my head left me a quadriplegic.

The challenges that go with the level of injury that I suffered seemed endless, but once I learned to manage my time and care, I found that it was not only doable but it is not as limiting as one might think. The nurses, doctors, and rehab staff at U of M all made sure that I not only understood my care but that I could actively and productively manage it.

The positive things I experienced while hospitalized were great friendships and great care. Also, while my injury altered everything about my life, I learned that it wasn’t the end of my life but a new normal. The negative impacts of my injury do not need to be mentioned. They are obvious.

SCI Access: Our newsletter topic is alternative/complementary therapies. Do you have any experience with any alternative therapies? If not, what are some less conventional things that have helped you with challenges you’ve faced while living with SCI?

VL: There are so many alternative therapies out there for people with SCI. You just have to be willing to look for them and to be open enough to try them. Things can be so scary, but you can’t surrender to that. You just have to push through it. Otherwise, your injury not only paralyzes your body but also your mind.

I do the normal ranges and movements in my physical therapy sessions, but I also do alternative things as well. Singing and teaching group fitness classes really help my lungs stay clear and highly functional. I say this in jest, but yelling at my kids everyday also helps a great deal. Going out regularly plays a huge part in helping me to stay strong and sharp. It challenges me in every way: physically, mentally, and spiritually.

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Vanessa Levin with her son
My art also helps a great deal. Even though my approach to it is extremely different than before, it is just as therapeutic. It also helps to keep my neck strong and all the gains I have made thus far active and present.

**SCI Access:** Do you have any advice to share? Any helpful tips, anecdotes, or thoughts about SCI in general?

**VL:** My advice to anyone with SCI is to face it head on. I truly know how terrifying it is. But the only person at the end of the day who is going to make you as strong, as healthy, and the best person you can be is you. Advocate for yourself. Don’t be afraid to tell your care workers, doctors, and family what you need and how you need it. Obviously, humor and kindness will help get those things better than anger and bitterness. Do not allow your injury to define you. You are more than that.

I am not brushing aside the enormity of spinal cord injuries. The challenges that we face are crippling, from the conversations with the doctors when they explain to you all that you will not be able to do, to the pain and helplessness you will experience. I am simply saying that for everything we face in life whether we are able-bodied or not, we have choices. Choose to deal with life challenges in a positive manner or choose the alternative. I have chosen to do it in a positive way as much as possible. My life is good. I have love, friendship, and purpose. For that I am grateful and that is the reason I get up every day.

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**Thank You to Santa Clara**

*By: Kristin Aho*

During the past couple of months, we have been blown away by the incredible response of research participants from Santa Clara Valley Medical Center! When we initially reached out to see if any of them would like to participate in our Site-specific study, titled “Bladder and Bowel Complications and their Impact on Quality of Life after SCI”, we expected that maybe a few people would contact us. As it turned out, phone calls and emails flooded in, sometimes completely filling our voicemail box! There were a few days when we could barely keep up. Since then, we have had the opportunity to interview many participants, and others continue to trickle in. The most remarkable characteristics of the SCVMC group are their enthusiasm for research and strong sense of community.

It has been great interviewing and speaking with folks from SCVMC, and their participation in our research here at U-M is truly valuable. Although we are not yet done with data collection, we are curious to see if any differences emerge between the predominantly Michigan and California-based groups. When we analyze the data and draw some conclusions, we will create a fact sheet and share it both with the participants in our research and on social media. As always, if you have any questions before then, please feel free to reach out to the University of Michigan Spinal Cord Injury Model System by calling 734-763-0971 or emailing SCI-model-system@umich.edu.
The University of Michigan Spinal Cord Injury Model System publishes SCI Access. This newsletter is designed to provide information on research, treatment, and social issues related to rehabilitative care, spinal cord injury and disability. Established in 1985, the University of Michigan Spinal Cord Injury Model System is supported by grant #H133N110002 from the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR), Administration for Community Living, U.S. Department of Health and Human Services, Washington, D.C.

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Editor: Rebecca Parten, LLMSW

We hope you enjoy this publication. Previous SCI access issues can be accessed at our website (above). You may request addition to or removal from the mailing list or report a change of address by calling (734) 763-0971. This newsletter is made available for informational purposes only and not for the purpose of providing medical advice. You should contact your physician to obtain advice with respect to particular medical issues or problems. The opinions expressed through this newsletter are the opinions of the individual author(s) and may not reflect the opinions of the U-M SCI Model Systems or the granting agency (NIDILRR).

What Do YOU Want to Know?

Do you have a burning question? An embarrassing one? One that has been in the back of your mind for some time? We want to hear about it! No question is too small, too silly or too extreme. We want to provide the information that you want most, and the only way we can find out what that is, is if you tell us!

So, don’t be shy! Please send us your questions (anonymously or with your name) by US mail, Facebook, Twitter, or phone. You can also access an electronic form by scanning our QR code with your smartphone or tablet.

We plan to post questions (but we will not use your name) and answers in the newsletter and on Facebook as space permits. Thank you for taking the time to let us know what you are most curious about!