



SPOKES

A Newsletter of the Rochester Spinal Association:
A Chapter of United Spinal Association



Dates to Remember:

- June 15th and 16th Adaptive Paddling and Cycling with Rochester Accessible Adventures. 7 Liffbridge Lane W, Fairport NY: 10 AM-1:00PM
- June 27th Peer Support Group Meeting: 5:00-7:00 at MCH, 6th floor lounge.. Dave Jenkins speaks about personal defense.
- June 29-30th— Gus Macker 3 on 3 Basketball Tournament-Downtown Rochester.
- July 10th -Open Board Meeting at MCH. 5:00-6:30, 6th floor lounge.
- July 25th Peer Support Group Meeting 5:00-7:00PM. MCH 6th Floor Lounge.
- August 21st Free Concert at Charlotte Beach: The band Brass Taxi at 7:00-9:00: Come picnic and mingle.
- August 22nd— Peer Support Group- 5:00-7:00PM at MCH, 6th floor lounge.

A Letter from the President

Greetings Everyone!

Spring is here (wet and cold) but I see it coming! We continue to grow and plan the future of the Rochester Spinal Association.

We continue to focus on our mission as we plan activities for the year. We have 2 grant opportunities to help those with spinal cord disability. Our newest grant promotes health and wellness. The **Wellness grant** can be used in many ways—from membership to a gym, payment for an adaptive yoga program, kayaking or cycling at the Erie Canal Boat Co., attendance at a cooking class to improve nutrition, to respite for primary caretakers. Grant money is available on a first come first serve basis. Please go to our website to fill an application and take advantage of this wonderful grant. (www.rochesterspinalassociation.org)

We also have a limited number of **Quality of Life grants** (up to \$2,500) a financial needs based grant that provides adaptive equipment not covered by insurance. You can find grant details on our website as well.

RSA had a Spring Fling event at the Henrietta Town Park on Sunday May 5th. It was wonderful to see some new faces, enjoy playing adaptive tennis with SportsNet, and eat great food at the taco bar! Thanks to Sue Shepard and all those who volunteered for organizing and setting up the event. Please consider coming to our up-coming events and monthly support group. Visit the website calendar to view the latest activities available.

We continue to pursue our strategic plan which includes the following areas: fundraising, urban outreach, and pursuit of an administrator. **You are welcome to come to our Annual open Board Meeting July 10th, 5:00PM at MCH 6th floor** and learn

more about what our Board is doing.

These are just a few of the many opportunities we have going for our chapter members. We continue to focus on our goal to be a strong and supportive clearinghouse of resources for individuals with spinal cord disability and their families and friends. See our new Resource Guide online.

As you can imagine, there is much work to be done and we hope you will want to help us by joining a committee, volunteering, participating in one of our upcoming events, or making a financial donation (every bit will help).

Happy Spring and Summer to all of you—enjoy and embrace the changes coming!



Sincerely,
Amy Scaramuzzino

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Picnic and Music at Charlotte Beach

Date: Wednesday, August 21st
Time: 5:30– 8:30pm
Brass Taxi plays 7:00 to 8:30PM
Charlotte Beach

We will get a pavilion and supply subs and drinks.
Bring a dish to pass if you can.
RSVP 585-234-3269



MEMBER SPOTLIGHT Brian Weber

Instant replay: Hot summer day, a date at the beach, young man in his physical prime. A playful back flip into the warm August waters of Lake Ontario. Gut piercing recognition that something is very wrong. Drifting down to the soft sandy bottom wondering when his companion will realize the gravity of the situation. It's amazing how deep 3 feet of water is when you are powerless to rise to the surface.

Brian's C3-4 injury left him paralyzed from the chest down. Despite this reality, his passion for physical activity burns like a furnace within. He forged this personal creed as a physical education major while in college. Now at this stage of his life, his beliefs are more important than ever and more consequential than most people will ever know. As a coach and mentor, he lives his personal philosophy, *"I feel physical activity is an important component to everyone's life. My reasoning for this statement is simple, one cannot be successful at anything if they cannot live long enough to be, due to dying at a young age because they are unhealthy and unfit."* He wrote this while in college before his injury and it has never been more relevant than right now.

The importance of team work can't be overstated regarding Brian's story. A team of health care professionals, care coordinators and most importantly a dedicated family help Brian move his passion to action. It took many months post injury to set up his house, transportation, equipment and dedicated care givers to help him maximize his functional independence while he navigated a less than supportive healthcare system.

Before you start any type of exercise program or diet you need to check with your doctor and get professional advice. There are many good references and guides for the SCI community on the United Spinal Association website. The Rochester Spinal Association is currently providing grants that can assist with injury prevention, physical training, nutritional counseling, and overall wellness for those living with SCI and their caregivers.

As a quadriplegic, he learned early on that many ailments are extremely dangerous to his overall health. Pneumonia, bladder infections, pressure ulcers, excess weight all conspire to compromise the quality of his life or end it. Over the past several years he has developed a total body wellness regime that builds the strongest possible defense against opponents that can kill him. This regime combines nutritional planning with a structured exercise program targeting his core strength and extremity tone.

Brian's diaphragm is extremely compromised. The simplest of functions, breathing, talking, coughing are all driven by the movement of your diaphragm. Maximizing this action is critical to maintaining respiratory health. Each morning to strengthen his core he stimulates the muscles of his abdomen using a personal electrical stimulation box. As electrodes attached to his stomach ramp up with power, he performs crunches to the best of his ability. Over the course of 5 years he has dramatically improved his trunk control and ability to cough effectively. This helps to keep his lungs clear and open. This also allows him to project his voice over the cringe worthy collisions of his offensive and defensive lines right before the screech of his coach's whistle.

We all know that an immobile body in a bed or wheelchair is at risk for skin breakdown. Nothing will throw the quality of your life into a garbage can faster than a pressure ulcer. Brian makes sure that he shifts his weight accordingly by changing his chair position at appropriate intervals. He also incorporates a Functional Electrical Stim (FES) bike (Restorative Therapies) into his workout regime. This exercise bike uses electrical current to inspire contraction of his legs and other muscles used to pedal the bike. In Brian's case, he stimulates his hamstrings, quadriceps, and gluteus muscles. Two times per week he rides





for 1 hour covering the equivalent of 11.4 miles. He believes that this activity helps keep his glutes built up, healthy and strong. This bike is also equipped with an arm attachment that electrically stimulates the muscles in his shoulders, biceps and forearms. At least three times per week he “arm rides” for 30 minutes covering about three miles. He has remained pressure ulcer free for 6 1/2 years.

Anyone who has ever tried to maintain or gain back a healthy body knows that exercise is only half of the equation. Some nutritionists will say that exercise is only 20% of the equation and the remaining 80% is what you put in your mouth. He has done an incredible job of “adjusting” his caloric intake. At the time of his injury, Brian weighed 210 lbs. Seven months of hospital food, muscle loss and physiological changes dropped him down to 170 lbs. Returning home and falling into a routine of three meals a day with regular snacks resulted in a 100 lb. weight gain within 1 year. He wasn’t pleased with the way he looked, it was very difficult to sit comfortably in his wheelchair and the weight made it much more of a struggle for his caregivers who were responsible for bathing, dressing and transferring him each day. Not to mention

the sky rocketing cholesterol now threatening his vascular health.

After some deep reflection he realized it was time to start living his personal fitness philosophy or become a victim of it. He started with his diet, not just how much he ate but what he ate. A typical day of eating will include a fiber bar for breakfast, an orange and almonds for lunch and a dinner that consists of lean meat and a decent sized portion of vegetables. Taste is critical. Spices and sauces all help him to make sure that his taste buds enjoy the experience. Grilled chicken and steak are two of his favorites accompanied by a large salad. He increased his intake of water, cut way down on the carbs and “junked” the junk food. At least during the week. Weekends are times to cut loose and he rewards himself with some high calorie meals and a few taste quenching snacks.

Brian has maintained this lifestyle combining diet and exercise for over 4 years now and currently

weighs 190lbs. This is the best he has felt since his injury. Not surprisingly, attending live sporting events is one of his favorite activities. Larger college venues offer good viewing options. Always the student, computer accessories allow him to engage his curiosity and enable real-time communications supporting his coaching activities. Our local wheelchair rugby team, the Rochester Wreckers benefit from his encouragement at practice and his watchful eye during tournament play.

A coach, a teacher, a motivator, he’ll tell you that looking back is only good for seeing how far you’ve come but it’s no good for setting a direction on where you’re headed. Brian can’t tell you exactly

what he’ll be doing 10 years from now. Becoming more active in the Rochester Spinal Association, a local chapter of the United Spinal Association is a priority for him. That’s a good sign for this organization and the SCD community that will rally around his example. Right now, he knows that the best way to position himself for the future is to stay as healthy as possible. With his drive to tackle life every day, we should hear this coach’s whistle for many years to come. —Scott Frail



WELLNESS GRANT

Living with spinal cord injury? Want to feel better?



We have grants available!

The Rochester Spinal Association, through the generosity of the Neilson Foundation, has funding available for individuals living with spinal cord injury and their caregivers.

These funds are intended to help improve the physical and mental/emotional health and wellness of individuals with SCI, and their caregivers, by paying for a wide variety of activities and/or equipment.



Who's Eligible?

Individuals with spinal cord injury and their caregivers, living in Monroe and the surrounding counties.

There are no financial requirements.

What's covered?

Activities and equipment that enhance individual wellness, including gym memberships, sports equipment, therapeutic massage, dance lessons, personal training, transportation and much, much more.

How to apply?

Download the application and instructions online at: <http://bit.ly/RSA-wellness>

Or, contact Chris Hilderbrant at chris@chrishilderbrant.com or 585-308-1546.

Social Support Group Meetings

Date: Thursday, June 27, 2019

Time: 5-7p

Location: Monroe Community Hospital

6th floor Fireside Lounge, Faith Bldg.
435 E. Henrietta Rd., Rochester, NY 14620
Park in Parking Lot #3 & follow the signs.



Topic:

Rochester Personal Defense, LLC offers a full complement of firearms, self-defense and pistol permit training classes for private citizens and Law Enforcement. The instructor's philosophy: "We will work with you in any way that benefits you and ensures you get the most out of your self-defense training."

At this meeting we will introduce the topic of self-defense and train 1-3 things you can use now. There will be a Q & A session at the end and the information will be used to develop a training class with more detailed instruction of modified techniques for wheelchair users.



SAVE THE DATE

4th Annual Red Solo Cup

September 30th, 2019

Locust Hill Country Club

More information to come!

Join us at the Gus Macker
3 on 3 Basketball Tournament
and Family Festival

June 29-30th at the Blue Cross Arena
8AM-8PM

RSA has Sponsored a Team and will have a
Table at the tournament!





RSA Guiding Principles

Our programs and services provide support and information to individuals with spinal cord disability and their loved ones, care providers and professionals in the Greater Rochester region of N.Y.



NYS Access Pass for an Individual

What is the Access Pass?

The **Individual Access Pass** permits a **resident of New York State with a disability**, as defined in the application, **free or discounted use of parks, historic sites, and recreational facilities operated by the New York State Office of Parks, Recreation and Historic Preservation and the New York State Department of Environmental Conservation**. For a description of these facilities visit www.nysparks.com and www.dec.ny.gov.

The pass holder may have free or discounted use of facilities operated by these offices, for which there is normally a charge – for example, parking, camping, greens fees, swimming.

The Individual Access Pass is not valid for waiver of fees such as those for seasonal marina dockage, group camp or cottage rental, performing arts programs, consumables (i.e. firewood, electric, or gas), campsite/ cabin amenities, reservations and registrations as well as some services or locations operated by an outside concessionaire.

Access Pass qualifications and requirements are described within the application. Please note the expiration date on the Individual Access Pass. It is your responsibility to reapply to obtain a new pass. There is no renewal process.

To ensure that your application can be approved for processing please be sure that all of the items below are included when submitting your application.

- * Complete all the Applicant Information in Part One of the application.
- * Enclose a copy of your current New York State Driver License, Non-Driver Identification Card, or a copy of your New York State tax return form IT 201 or IT 150.
- * Enclose a passport size photo (2" x 2").
- * Sign and date the Authorization and Certification.
- * Enclose the proper organization certification OR Have your physician complete all the information in Part Two.

• This application cannot be processed on site at any location.

Mail application, enclosing all required materials to:

**Access Pass
 New York State Parks
 Albany, NY 12238.**

Please allow 2 - 4 weeks for processing of this application.

For questions contact our office during regular business hours.

518-474-2324 TTY/TDD through 711 Relay Service.

To learn more or get the Guidelines and application go to:

<https://parks.ny.gov/admission/access-pass/default.aspx>