The University of Michigan’s Department of Physical Medicine and Rehabilitation (PM&R) is excited to announce the arrival of ReWalk™ at our Briarwood MedRehab facility! The ReWalk™ exoskeleton allows an ambulation and rehabilitation alternative to wheelchair users, enabling people with paraplegia and other types of lower limb dysfunction to stand, walk, and climb stairs.

The ReWalk™ offers patients a variety of benefits, in various aspects of their life. It can help to increase daily function by allowing the user to have easier access to upright exercise, to have the ability to stand eye-to-eye with someone and to access the environment from an upright position. It also helps to overcome some of the practical challenges associated with being in a wheelchair, such as improved access to buildings without a ramp.

Because it helps people to walk, using the ReWalk™ is also likely to offer health benefits to users, including:

• improved bone density
• decreased body fat
• improved bowel and bladder function
• decreased pain
• decreased spasticity
• improved sitting posture
• improved cardiorespiratory function

The ReWalk™ system has now been approved by the FDA for use within Rehabilitation Centers in the United States. The University of Michigan is proud to be the only rehabilitation site in the Midwest to have the ReWalk™. A home unit, designed for personal use, is currently undergoing FDA approval and is expected to be available in 2013.

It is home use of the ReWalk™ system which appears most likely to improve people’s lives, providing users with an opportunity to expand their horizons with a new independence. Whether it is going for a walk, talking with friends and family, standing at a stove and cooking, retrieving an item from a high shelf, or getting a hug while standing up, the ReWalk™ has the potential to make little changes that can have a big impact.

Training with ReWalk™ is covered by insurance companies as part of physical therapy visits; as such, it requires that the user has functional goals and demonstrates progress through the sessions. The training program is designed to occur over eight weeks with sessions three times per week. Training activities include walking, standing, sitting, and working at ascending and descending stairs.

Continued on page 2
Director’s Corner

By: Anthony Chiodo, MD, Co-Director UM SCI Model System

Welcome to this new issue!! As the weather starts to warm, our thoughts start to move toward getting out of the house and spending time outside. So it is with excellent timing that this newsletter focuses on issues related to physical activity and exercise.

There is a great review on physical activity by Drs. Chadd and Peterson. This issue also contains two articles about the ReWalk, a robotic exoskeleton for walking. Finally, we have included several articles that discuss adaptive sports and recreation that are accessible to many individuals with spinal cord injury (SCI). Together, they should give you reasons to be active as well as ideas for how to do so.

When it comes to needing physical activity, we are all alike. There is no question that for ALL people, the advantages that exercise provide are great – better control of weight and blood sugar; decreased hypertension and heart disease; decreased risk for stroke; better strength, endurance, and functioning; and improved mood and quality of life. And this is just for routine exercise. What are the possibilities if true fitness is achieved?

The potential benefits of high levels of fitness have not been well studied in wheelchair users but it is likely that they are similar to what has been found in other populations – that individuals who achieve a high level of fitness show increased life expectancy and improved quality of life. Paralympic athletes are among those who have achieved this high level of fitness and this issue also includes information about the road to the Paralympics and the story of one Paralympian.

The Paralympics are exciting and motivating to watch because they provide us examples of possibilities – people with disabilities who are also world class athletes. Numerous other examples exist of individuals with SCI and other physical disabilities who compete in marathons, climb mountains, and take on the world. The examples are nearly endless!! Of course, some of these achievements can only be made by the rare athlete - we all can’t throw 100 mph fastballs or win a gold medal. But we can improve our health and experience joy through participation. The thrill is in being out there; and that can be victory enough.

So read on. And think of the possibilities. And when the weather breaks, head on outside, whatever you do!

Ongoing Opportunities for Exercise and Physical Activity at UM MedRehab

**Momentum- Advanced Gym Clinic** – Mon, Wed, Fri 12:00-1:30
- Designed to provide a boost to concurrent therapy efforts or as a beyond therapy program
- Supervision, help with set up and a minimal amount of physical assistance is available for attendee
- Use of regular and specialized equipment, included FES cycle, standing frame and WBV (with evaluation and permission
- Requires purchase of a punch card to attend at the cost of 10 visits for $100

**Post Rehabilitation Gym Clinic** – Mon-Fri 7-9am, 4-6pm and Mon-Wed-Fri 12-1:30
- Designed to be a transition from skilled therapy to an independent exercise program
- $50 per month fee; Can come as often as you wish during the designated times
- Participants must be able to exercise independently, as no physical assistance is available
- Includes use of standard gym equipment, including treadmills, elliptical, bikes, and strengthening / weightlifting equipment

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ReWalk™
Continued from page 1

In addition to focusing on gait, the goals of therapy during ReWalk™ training involve improving dynamic standing balance and reaching, bowel and bladder functioning, and blood pressure control. Sessions will also allow a user to evaluate whether they have the capacity to use a home unit in the future.

Use of the ReWalk™, though, is not for everyone; certain characteristics are required in order to be successful. The ideal candidate for ReWalk™ use include those with:

- Complete or incomplete spinal cord injury at T8 or below
- Good trunk control and body awareness
- Good upper extremity function and range of motion
- Adequate lower extremity range of motion to allow for ambulation
- Minimal lower extremity spasticity
- Independence with wheelchair mobility and transfers
- Active participation in a standing or gait program (KAFO, RGO, standing frame)

In addition, every person who is considering ReWalk™ use should be performing a home exercise program that focuses on flexibility and balance prior to using the device.

Finally, there are some factors that may limit use of ReWalk™. Among the conditions that may prevent individuals from being considered as candidates are: uncontrolled spasticity or clonus’ infection, pressure sores or DVT, pregnancy, cognitive impairment, and severe concurrent medical conditions.

If you are interested in being evaluated as a candidate for ReWalk™, please contact MedRehab Briarwood at (734) 998-7888. A prescription from your physician will also be required.
Featured User: Mary Armbruster

Mary Armbruster is a 24 year-old Ann Arbor native who sustained a T10 ASIA A (complete) spinal cord injury (SCI) in 2011. She completed inpatient rehabilitation on 6A at UM’s University Hospital and went to MedRehab for outpatient therapies for several months afterwards. Recently, though, her physiatrist had recommended additional physical therapy and Mary was asked if she wanted to be part of the ReWalk™ training program that was just coming online at MedRehab.

Mary started using the ReWalk™ in early February of 2013. She attends outpatient therapy at MedRehab where she uses the system twice a week with the assistance and guidance of her physical therapists, Krysten Salla, DPT and Christine Wallis, MSPT. In March, we sat down with Mary following a treatment session to learn her perspective on using this new technology.

SCI Access: Mary, prior to being involved in the ReWalk™ training program, what have your therapies included?

Mary: In my outpatient therapies I have focused on wheelchair skills, core and upper-extremity strengthening, weight-bearing and walking exercises. I stand in a standing frame several times a week, and have used the Lokom- at and KAFOs to stretch and strengthen my leg muscles and to improve circulation to my lower extremities.

SCI Access: You recently began using the ReWalk™. How has your training been going?

Mary: After using the ReWalk™ for a little over a month in physical therapy, I still require some assistance with the weight shifts, though with each session it gets easier to maneuver on my own. Using the ReWalk twice a week makes it easier to stretch my leg muscles daily, as they relax faster.

SCI Access: How did you feel after first using the ReWalk™? What challenges have you encountered?

Mary: Because I was used to standing and walking often, my first time standing and walking in the ReWalk™ did not feel entirely foreign to my body. Though when the machine stands, it does so rather quickly and thus abrantly stretches all the muscles that tighten while sitting, which can be uncomfortable. It is not a machine that you just strap yourself into and it walks for you, there is a large learning curve to ascend while perfecting the weight shifts and body positioning.

SCI Access: What do you see as benefits of using the ReWalk™?

Mary: My favorite part about being in the machine is that I am pretty much back to my old height, as opposed to looking up at everyone in my wheelchair, or looking down on everyone from the Lokomat or KAFOs. It is very easy and natural to stand and chat with people at eye-level.

SCI Access: How would you like to see the ReWalk™ fitting into your future?

Mary: In the future I can see myself using the ReWalk™ for social outings with friends that involve walking around, for example going to the park or walking around the Art Fair. It is also exciting to think about the current technology and how much easier a lighter-weight, and “smarter” ReWalk™ could be for every-day use in place of a wheelchair.

Mary Armbruster using the ReWalk system with the assistance of her physical therapists at MedRehab
Physical activity is critical for maintaining health and preventing chronic conditions such as heart and lung diseases, obesity, diabetes, and depression. In contrast, not moving is now recognized as the primary cause of cardiovascular and metabolic (“cardiometabolic”) problems, and is the strongest known predictor for muscle and bone deterioration, general weakness, and early mortality.

For individuals with SCI, the challenges to engaging in physical activity can be many. To begin with, the common types of exercise used by the general population are not an option for many people with SCI. In addition, relatively few fitness facilities have exercise equipment that is wheelchair accessible and even fewer have the types of specialized equipment that may be of most benefit. Moreover, published physical activity recommendations are often not relevant to those who cannot walk.

Too often, this combination of barriers leaves people with SCI feeling as though they cannot participate in physical activity or exercise at all. As it turns out, though, exercise and physical activity are even more important for those with SCI as it helps to ensure maintenance of healthy functioning of the body as a whole.

**Body Changes and Secondary Conditions after SCI**

Paralysis can lead to metabolic changes that impact cardiovascular health. Muscles that are not moved on a regular basis atrophy (weaken or deteriorate). At the same time, the lack of muscle movement and reduced energy expenditure results in an increase in body fat. If individuals remain sedentary and don’t consciously engage in exercise and physical activity, the body’s metabolism will decrease and so fewer calories will be burned in the course of daily activities.

As a result, individuals with SCI have higher rates of obesity and diabetes than the general population. Obesity can then lead to cardiovascular disease and the higher levels of “bad cholesterol” (low density lipoprotein, or LDL). In fact, cardiovascular disease is becoming the leading cause of death among those with chronic SCI.

Loss of bone density (osteoporosis) is another significant problem after SCI. The strength of bone is related to its density. Standing and walking stimulate healthy bone growth. After SCI, atrophy of muscles and reduced levels of weight and compression placed on the bone result in rapid loss of bone mineral density of up to 50% in the first year, with the hips being the primary location of loss. This results in an increased risk of bone fracture from even the smallest trauma.

Finally, because of both paralysis and lifestyle, adults with SCI tend to be much less active than adults in the general population. This trend corresponds with increased secondary and co-morbid conditions, including pain, fatigue, arthritis, and cardiovascular disease.

**Benefits of Physical Activity and Exercise**

The good news is that individuals with SCI can reduce their risk of acquiring these secondary conditions and improve their health by engaging in physical activity and exercise. Exercise can help to reduce risk of fractures by stimulating new bone formation or preventing bone loss. In particular, muscle contraction exercises conducted through electrical stimulation can have positive effects on bone density.

In addition, exercise can reduce metabolic risk factors. Research studies have found that people with paraplegia and tetraplegia who engaged in higher levels of structured exercise have less risk of obesity, less insulin resistance (a precursor to diabetes), and higher levels of the “good cholesterol” (high density lipo-
protein, or HDL) that help protect against heart disease. When it comes to fighting cardiometabolic diseases, the specific type of exercise or physical activity is not as important as simply doing something to stay active on a daily basis.

- Exercise and physical activity may also help to reduce or prevent many other common health complications. Research conducted with individuals with SCI has found,

- Lower levels of urinary tract infections (UTI’s) among those who did general exercise at least once a week.

- Fewer recurrent pressure ulcers among those with higher levels of fitness and greater participation in exercise as compared those individuals with SCI who were inactive.

- Starting an exercise program or sports participation may improve overall psychosocial well-being after SCI.

- A combination program including both strength training and aerobic exercise may decrease overall pain levels.

Types of Activity and Exercise

It can be helpful to clarify what is meant by the various terms and types of activity and discuss their roles in managing health.

Baseline activity is defined as the smallest increments of body movements that increase energy consumption above simply sitting quietly. These activities may include lightly pushing a wheelchair or lifting very light objects. Consistent with this definition, individuals who do only baseline activity are not sedentary, per se, but are still considered to be inactive.

Sedentary Behavior Reduction refers to increasing the amount of baseline activity, usually in preparation to engage in physical activity. It is the “first step” to health preservation for persons with SCI.

Physical Activity is defined as any type of movement by skeletal muscles that require energy expenditure. Regular physical activity is considered necessary for health maintenance, and is recommended to sustain a healthy body composition, cholesterol/lipid profile, blood pressure, and psychological well-being.

Lifestyle Physical Activity refers to energy expenditure that occurs as part of your daily routine or leisure activities (e.g., gardening, biking, housework, wheelchair mobility). Some lifestyle physical activity is certainly better than no activity at all, and for most health outcomes there is a positive relationship between the amount of activity accomplished over time and the magnitude of health gain.

Exercise refers to physical activity that is performed to develop or maintain fitness. Structured exercise is necessary for targeting specific areas of health and functioning. Structured exercise falls into three categories: (1) cardiovascular, (2) strength training, and (3) range of motion (stretching).

- Cardiovascular (or aerobic) exercise typically involves sustained movement at low to moderate intensity which increases blood flow and oxygen supply to the muscles, raises the heart rate, and increases breathing rate for a sustained period of time (10-30 minutes, or more). The repetitive movement may be voluntary such as using an arm crank, wheelchair propulsion, or swimming; however, involuntary muscle movement through electrical stimulation (e-stim) of paralyzed muscles can also provide aerobic exercise.

- Strength training results in increased muscle mass and more efficient muscle contraction. Resistance training can involve muscles under voluntary control (such as the arms of individuals with paraplegia) to build strength for functional tasks like transferring. It can also involve paralyzed muscles through electrical stimulation to improve overall body composition. Resistance training typically uses free weights, weight machines or elastic bands.

- Stretching improves the range of motion of joints, as well as the extensibility of muscles, tendons and ligaments to prevent contractures. Collectively, these factors serve to improve or maintain adequate flexibility for activities of daily living, transfers, and wheelchair positioning. Stretching can be done by oneself (actively) or with assistance (passive stretching).

Fitness is a combination of aerobic capacity, resistance to fatigue and muscle strength capacity. The ability of an individual with SCI to ambulate, transfer or engage in any activity depends on the body’s strength, resistance to fatigue and functional range of motion. In particular, mobility skills for transferring or self-care depend largely on muscular strength and power output, particularly of the arms, shoulders and trunk.

- To improve aerobic capacity, upper-body ergometry (arm cranking exercise), wheelchair propulsion, and e-stim assisted strategies such as cycling or rowing, can be beneficial.

- To improve muscle power, electrical stimulation-assisted exercise can be beneficial.

- Swimming may also be beneficial in improving functioning and self-care ability, including transfers and lower extremity dressing, for individuals with paraplegia.

Continued on page 15
From August 29th to September 6th 2012, the world watched as elite athletes with physical, cognitive, intellectual and sensory impairments competed for Gold at the London 2012 Paralympic Games. While prime time coverage in the United States was disappointing and all too brief, it still provided an opportunity to learn about and be inspired by the athletes and their accomplishments.

**Background on the Paralympic Games**

The Paralympic Games are the elite international athletic competition for individuals with disabilities and, according to the Paralympic website “act as a primary vehicle to change societal perceptions and leave lasting legacies.” The values of the Paralympics - Courage, Determination, Inspiration and Equality – are represented in its flag.

The Paralympic movement grew out of the Stokes-Mandeville Games, an adaptive sporting competition held in 1948 for British World War II veterans with SCI. The first official Paralympic Games were held in Rome in 1960 and, while they were only open to athletes in wheelchairs, included 400 athletes from 23 counties. When athletes with different types of disabilities were included in 1976, 1,600 athletes from 40 countries competed at the Summer Paralympic Games.

Since 1988, the Paralympic Games have been held following the Olympics, in the same cities and venues. The London 2012 Games saw 4,250 athletes from 154 countries compete in 20 different sports. 2.7 million tickets were sold to spectators (breaking previous records) and it is thought that over 3 billion people from around the world watched at least part of the Paralympic Games. The United States sent 227 athletes, including 133 men and 94 women to the London 2012 Paralympic Games as part of TeamUSA.

**Paralympic Classifications**

The International Paralympic Committee groups athletes according to sport-specific classification systems. This is to ensure that success and winning is associated with the skill, fitness, endurance and mental focus of the athlete as opposed to the degree of activity limitation associated with an impairment.

In addition, sports are categorized by the diagnostic categories or functional limitations of athletes. Individuals with SCI are typically grouped with other individuals who are paralyzed and/or use wheelchairs and are included in 21 of the 27 sports to be offered at the upcoming Paralympic games. These include summer events such as archery, baseball, cycling, wheelchair fencing, and rugby, and winter events such as alpine skiing, biathlon, and sled hockey.

**Finding the Athletes who Compete**

The identification and recruitment of athletes for Paralympic competitions begins at the local level through community programs and military and veterans groups. A tier-based system of adaptive sports is slowly emerging and with it a pipeline for the Paralympics. Athletes are identified and recruited by coaches, technical officials and current athletes as they compete.

Once an athlete is identified as having high-performance potential, the Emerging Sports Manager from the US Paralympic Program makes the connection between the athlete(s) and their local program and the appropriate Paralympic sport coaches and directors. The athlete is then connected to local training resources and encouraged to participate in select camps and competitions.

**Military Partnership**

Military personnel and veterans with disabilities receive specific encouragement and opportunities to be involved in adaptive sports. Specific programs exist to provide post-rehabilitation support and mentoring to American servicemen and women, including Warrior Transition Units and...
Wounded Warrior Battalions / Detachments. Veterans are introduced to adaptive sport techniques and opportunities through clinics and camps and are also connected with ongoing Paralympic sport programs in their hometowns.

You do not have to be a star athlete to get involved in adaptive sports and exercise. Michigan offers a number of options for trying out and increasing your involvement in numerous adaptive sports at a variety of skill levels.

Through partnerships with the U.S. Department of Defense and the U.S. Department of Veteran Affairs, the USOC Paralympic Military Program has impacted the lives of thousands of injured military personnel and veterans.

**Community Based Adaptive Sport Organizations**
The U.S. Paralympics Program also partners with community-based adaptive sports organizations to address the disparities in participation in sports, physical activities and exercise that individuals with SCI and other physical disabilities experience. This has the greatest potential for improving physical health, as community organizations and programs are open to youth and adults with physical and visual disabilities regardless of skill level.

Through these partnerships, the U.S. Paralympics enables people with disabilities to gain a sense of independence, a positive attitude, access to social opportunities, and personal growth through the challenges that sport and recreation present. Research indicates that participation in adaptive sports leads to reductions in stress, depression and anxiety and improvements in overall health, quality of life, self-confidence, general level of activity, feelings of empowerment, and satisfaction with life.

**Getting started**
While the level of competition associated with being involved in the Paralympics involves a high degree of commitment and athleticism, you do not have to be a star athlete to get involved in adaptive sports and exercise. Michigan has a number of options for trying out and increasing your involvement in numerous adaptive sports at a variety of skill levels.

We have included information about some state-wide and national adaptive sporting organizations through the newsletter. If you are having difficulty locating an adaptive sports club near you, please contact Michigan Sports Unlimited, INC (at 998-771-5530 or www.misportsunlimited.com ) and they will be able to point you in the right direction.

**Being Involved as a Volunteer**
Finally, whether or not you decide to play a sport or compete as an athlete, please consider volunteering. Without volunteers not a single adaptive sports club in the United States could operate. Throughout the country, hundreds of volunteers - old and young alike - arrive day after day to provide endless hours of adaptive sport lessons, equipment maintenance, office work, food, and endless amounts of smiles, encouragement, and support.

To learn more about the Paralympics, go to http://www.paralympic.org/ or http://www.teamusa.org/US-Paralympics.aspx.

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**Adaptive Sports and Recreation Organizations - National**
Paralyzed Veterans of America (PVA): www.pva.org or 800-424-8200
Michigan PVA: www.MichiganPVA.org or (800) 638-MPVA (6782)
Michigan PVA sponsors wheelchair sports and recreation programs throughout Michigan, both summer and winter. Our national organization offers bass fishing, trapshooting, billiards, and bowling tournaments to all chapter members. Individuals with SCI can become associate members even if they are not veterans.

Wheelchair and Ambulatory Sports USA: www.wsusa.org
A member organization of the US Olympic Committee and national 501(c)3 organization consisting of grassroots programs which are arranged into 14 Regional Sports Organizations.

Disabled Sports USA: http://www.disabledsportsusa.org/
Provides national leadership and opportunities for individuals with disabilities to develop independence, confidence, and fitness through participation in adaptive sports.
Darlene Hunter: Profile of an Athlete and Educator

By Eric A. Appleberry, DDS, MS

As a child Darlene Hunter lived with her family on a gravel road in a rural area of Oakland County, Michigan. She often accompanied her father while he worked, but one day in November, 1986, doing so changed the course of her life.

While riding with her father in the open cab of a road grader (he did the road grading for the neighborhood), the vehicle hit a hole in the road and lurched, causing four year old Darlene to tumble out. Before the grader could be stopped, the rear wheel had run over Darlene’s midriff, causing a T-10, complete, spinal cord injury (SCI) and internal injuries.

Darlene’s father scooped her up, ran back to the house and then drove her to the nearest hospital - Huron Valley - where it was determined she had internal bleeding. Darlene was then transferred to St. John’s Hospital in Pontiac, where the surgery she had to stop the bleeding involved removing six inches of her intestines. After recuperating at St. John’s for two weeks, she was sent to the University of Michigan’s Mott Children’s Hospital for rehabilitation where she remained for almost three months.

At home, after the SCI, Darlene relates that she was not “babied” at all. In part, this was because her mother also had Darlene’s six-month old brother to take care of, but also because her parents consciously resisted the natural impulse to help her do everything. They wanted her to develop as much self-sufficiency as possible. As a result, Darlene quickly learned to crawl, get in-and-out of chairs and go wherever she wanted to around the house. Mostly, she left her wheelchair out on the porch.

Darlene’s parents wanted her to be able to do things that “normal” kids do in childhood. Their backyard became a gathering place for other children in the neighborhood. It was there that Darlene taught herself how to swing on the swing set, swim in the pool and jump (bounce) up and down on the trampoline. Darlene’s father even attached shoes to the pedals of a bicycle (one that had training wheels) so she could go biking with her friends by using her hands to push down on her knees to move the pedals.

During her early years at elementary school, there were several children with disabilities at Darlene’s school, so the other kids in her class didn’t think of her as “different”—and she got along fine with them. But three times a week, the children with disabilities were taken out of their regular class for a 45 minute PT/OT session. In Darlene’s case, this meant that she was put in leg/body braces that went up to her chest so she could “walk” by leaning to one side in order to then swing a leg forward. It was stiff, slow and Darlene “hated” them.

For her upper elementary grades, Darlene transferred to a school that didn’t have any other children with disabilities and here Darlene wasn’t as well accepted. But two years later, in Middle School, she had the good fortune to have two very thoughtful teachers - Mr. Meyer and Mr. Penrod - who didn’t put up with anyone treating others rudely. They made sure that Darlene was on the track team and was a part of all class activities, including the 8th grade class trip. During fire drills they even carried Darlene up and down the stairs.

After high school, Darlene attended the University of Arizona, where there was a good coach in wheelchair track racing. She was a good student and graduated with a BA in psychology & double minor in political science & special education. It was during her college career, though, that Darlene discovered that she liked wheelchair basketball better than track racing. As a result, finding universities that provided coaching in wheelchair basketball influenced her decision about where to obtain additional education.

She enrolled at the University of Texas, Arlington to earn her Masters in Social Work then moved onto Texas Woman’s University, Denton to obtain a PhD in Family Studies. Darlene continued to...
pursue both wheelchair basketball and education while taking online graduate classes through the American College of Education, achieving additional Masters and EdD degrees.

All the time, effort and dedication she gave to wheelchair basketball eventually paid off in a very big and public way. Darlene was selected as one of the twelve elite athletes to be part of the USA’s Woman’s Wheelchair Basketball Team that competed in the 2012 Paralympics, in London, England. Her team came in 4th place, losing to Australia in a semi-final game by just one point.

Darlene is now competing in the early wheelchair basketball trials that are already underway for the next Paralympics (the 2016 summer games in Rio de Janeiro in Brazil). These trials occur each year in each country that send athletes to the Paralympic Games, to progressively rank the many players according to their level of skill and disability, and lead to the final selection of twelve players to make that country’s team. Then, the eight top-ranked men’s teams, and the ten top-ranked women’s teams in the world get to compete at the Paralympic Games.

When not competing or practicing, Darlene works for the American College of Education (the on-line university where she herself did graduate work) as their Director of Training & Development. The job involves selecting educators to be their teachers and training them how to teach in an online system.

By teaching teachers how to effectively teach, Darlene feels she ultimately is contributing to the education of great numbers of Americans. She finds this very satisfying. She also appreciates the convenience of being able to perform her job from her home in Arlington, Texas.

Darlene also finds time to do volunteer work coaching the Dallas Jr. Wheelchair Mavericks Basketball team. This prep team is for children under the age of twelve, and uses 8 ft. high baskets. Through volunteering, Darlene helps these budding athletes to develop skills that will nurture both their physical and emotional health.

With regard to her own health, Darlene reports relatively few problems and feels her physical activity has contributed to this. That is not to say that she has not had to manage medical issues. At the age of fourteen, she needed to have rods placed in her back to correct a scoliosis (abnormal curvature) of her spine. Nine years later, when she was 23, these needed to be replaced when one of the rods broke, causing an infection in one of her vertebrae.

These days, Darlene shares her life and home in Arlington, Texas, with Jason Nelms, who also has a spinal cord injury (T-12, incomplete). Jason owns the Arlington wheelchair manufacturing company Per4max, which specializes in custom built sports chairs. He is also an athlete, having played wheelchair basketball for 18 years and been part of the USA Men’s Wheelchair Basketball team that won the bronze medal at the 2012 London Paralympics.

Reflecting back on her life growing up, Darlene greatly credits her parents for her sense of independence as well as confidence to set goals and work to accomplish them. She knows it must have been very hard at times for them to “sit on their hands” while she was struggling to do something that was difficult. But she is very thankful to them for this.

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**Upcoming Adaptive Sports Events**

- **Michigan Victory Games**
  - [http://www.michiganvictorygames.com/](http://www.michiganvictorygames.com/)
  - May 16-19, 2013, Michigan State University, East Lansing, MI

- **Thunder in the Valley Games**
  - May 30th - June 2nd, 2013, Saginaw, MI

- **Michigan State University Wheelchair Tennis**
  - Every Thursday night from 6-8 p.m. This event is open to all ages and free of cost. For more information please contact orlando@ath.msu.edu

- **Tennis on Wheels Wheelchair Tennis Lessons sponsored by Athletes Unlimited**
  - Wednesday evenings 6-8pm – June 6 – August 29, 2013 at the Southfield Civic Center. $10 per person for more information please contact Phil Woods at 810-964-1111 to register for this event.

- **Adaptive Sailing Clinic: June 14, 2013**
  - Contact Sports@maryfreebed.com or 616-242-0351 - Mary Free Bed Wheelchair and Adaptive Sports Program 235 Wealthy SE, Grand Rapids, MI

- **Jr. Wheelchair Sports Camp: July 29-August 2, 2013**
  - 5-day Wheelchair Sports Camp for youth with physical disabilities, ages 7 to 18 years old. 8:30am-4:00pm at Grand Valley State University. Free to day campers and $175 for overnight campers who live more than 45 miles from GVSU. For more information and to get an application for camp please contact sports@maryfreebed.com or 616.242.0351.

- **Kayaking and Waterskiing sponsored by Michigan adaptive sports**
  - June 28, July 26, August 23, 2013 at Pontiac Lake. Pre-registration required. Learn more at Michiganadaptablesports.org.

- **Sports-Tacular: September 6-8, 2013**
  - Michigan Adaptive Sports organizes a camping experience which includes Kayaking, Hand-cycling, fishing, golf, tennis and more. This takes place at Camp Dearborn. For more information on this event and registration information please check out the Michiganadaptablesports.org website. open to all ages and free of cost.
Handcycling 101

By: Bryan Wilkinson, Ann Arbor Center for Independent Living

Handcycling is a physical activity similar to bicycle riding. The rider moves the wheeled vehicle through their own effort and energy, providing power through movement of their arms as opposed to the legs.

Handcycling is a recreational activity, a type of exercise and a sport that is increasing in popularity. In part, this appears related to how it allows individuals with functional limitations to be active either individually, with a group or team, or with family members. Perhaps more importantly, because handcycling is so similar to bicycling, people with and without disabilities can enjoy it together.

The handcycle itself is a non-motorized vehicle in which propulsion is provided by arm movements. Most handcycles are tricycle in form, with two coasting rear wheels and one steerable powered front wheel. However, the exact design varies depending on the requirements of the riders, use and terrain.

Having the stability of the handcycle low to the ground adds a level of comfort and being able to lay back in the seated position maximizes the push and pull of the hand crank, resulting in a more efficient ride. It’s not hard to reach speeds from 10 to 30 miles per hour on a handcycle.

Who can handcyle?

Individuals with most types of physical disabilities can find a handcycle to accommodate their level of ability and functioning. The primary requirements are having the ability to transfer (with or without assistance) and having sufficient arm movement, strength and range-of-motion to power the cycle. Hand functioning is not required, as individuals can use adaptive attachments to keep their arms on the pedals. Similarly, problems with balance can often be accommodated for through the design of the handcycle.

Selecting and Purchasing a HandCycle

If you have never handcycled or are a relative beginner, it is important that you buy a handcycle that is adjustable. Your experience and ability level may also influence the model of handcycle that you choose or that will best fit your needs. You will find that handcycles with fewer moving parts will be lighter and have a stronger frame; this will result in a much faster handcycle. It will take time and practice to know exactly what is right for you.

If you are not sure what you want or need in a handcycle, try and locate a company or organization that may offer opportunities to try different models and talk to experienced handcyclists. The Ann Arbor Center for Independent Living (CIL), for example offers a weekly cycling program from the spring through fall that offers such an opportunity.

There are several handcycle manufacturers to choose from: TopEnd, CarbonBike, Quickie, Freedom Ryder, Schmicking, Rio Mobility (attachable), Varna, Reactive Adaptations, Hase, Handy, Lasher Sport, Amtryke and Maddilne. In addition, as the sport begins to become more popular, there are more manufacturers coming onto the market.

For beginners, a TopEnd Force 2 or a Quickie Shark are good options as the transfer is easier from an elevated seat. TopEnd also creates a handcycle that some of the top handcyclists in the world are using to compete. While some of these top competitive handcycles can be pricey, there are a lot of options and models that are just as nice and less expensive and will get you on the trail.

Handcycles can be purchased in a variety of ways. Some durable medical equipment (DME) companies are authorized dealers for handcycles and so can access most of the brands listed in this article.

Some models of handcycle can be purchased directly through the manufacturer. There are also websites that sell new and used cycles such as www.BikeOn.com or www.HandcycleTrader.com.

Sometimes insurance companies may provide funding to purchase a handcycle as a way of main-
taining health and wellness. Community organizations and foundations may provide additional options. If you have already been handcycling for more than two years, you may be eligible to obtain funding through Challenged Athlete’s Foundation (CAF), or through a group called Bikes for the Rest of Us.

**Handcycling Organizations, Clinics and Events**

There are now many ways to get into the sport of Handcycling in Michigan. Depending on where you live these organizations can help you get started. On the east side of the state, the Ann Arbor Center for Independent Living, Michigan Sports Unlimited, and Programs to Educate All Cyclists (PEAC) in Ypsilanti are all experienced programs and offer handcycles to use. On the West side, Mary Free Bed Rehabilitation Hospital, Wheelchair & Adaptive Sports, and Kentwood Parks & Recreation have established programs for experienced riders and people new to the sport.

The Ann Arbor CIL runs an annual, 4-day, all inclusive cycling event, the Great Lakes Independence Ride, the first weekend in August. This is an opportunity for people with all abilities to ride across the state from Lake Michigan (St. Joseph), to Ann Arbor. You can participate in all four days (260 miles) or one, two or three days depending on your schedule and abilities.

**Where to ride**

For beginners, the best trail systems are the trails that used to be railways. They offer less slope and the profiles (hills) are not as steep. A majority of these trails can be located by going to www.TrailLink.com. The Huron Valley Rail-Trail is a 10.5 mile asphalt trail near South Lyon, Michigan. The Huron River Greenway Border-to-Border Trail is 13.6 miles on asphalt and crushed stone near Ypsilanti.

Michigan’s beautiful lake shores and tree covered trails offer some of the nicest places for handcycling. Kensington Metro Park during the summer months offers a splendid trail with scenic views and varying hills to push you hard. It’s well worth it to take a look at your own local metro parks.

**Safety Considerations**

Because the sport is fairly new, motorists are not looking out for the close-to-the-ground and so low-profile cycles may be at increased risk of accident, especially crossing...

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**Interested in Participating in a Research Study Examining Quality of Life and Thinking after SCI?**

We need people ages 18-85 who have had a traumatic spinal cord injury (SCI) to participate in a study that will help us learn about quality of life, thinking, memory, and functional abilities in people who have SCI.

**Why?** We are working on addressing environmental barriers to treatment in clinical rehabilitation, and are adapting measures for use in SCI so that doctors, researchers, and policy makers can better understand how having an SCI affects peoples lives.

**What is involved?** Voluntary participation in two 5-hour long visits to the Department of PM&R to complete measures examining thinking, memory, and functional ability, and to take questionnaires covering various aspects of quality of life.

**Benefits**

- Knowing you have helped researchers, clinicians, and policy makers better understand cognition, functional abilities, and quality of life for individuals with SCI.

**Qualifications**

- You must have had a traumatic spinal cord injury (i.e., trauma from a car accident, fall, etc.)
- You must be able to read, speak, and understand English
- You must be 18-85 years of age

**Interested?** To learn more about this study or if you are interested in participating, please contact us:

(734) 763-3805
PMR-UMROAR@med.umich.edu

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*Continued on page 14*
SCI Research Registry and Randy Charon, Super Subject

By: Rachel Hartwig

The UM SCI Research Registry was developed as a way to connect individuals interested in participating in research with studies associated with spinal cord injury (SCI) being conducted at the University of Michigan. Joining the Registry involves providing your name, contact information, and a limited amount information about yourself and your injury.

As researchers develop studies and work with Registry coordinators to recruit potential participants, we do an initial search for individuals who may be eligible. When a match is found, we contact you to give you some information about the study. After 2 weeks, if we have not heard from you telling us that you are not interested, we pass along your contact information and some basics about you to the coordinator of the new study. This individual will then contact you to tell you more about their specific study and give you the option to participate.

Individuals with SCI enrolled in Registry are likely to be asked to participate in a wide variety of studies. Most are telephone surveys, but some are medication trials or clinical service interventions. The number of studies you are contacted about depends on how many come through the Registry from being abled-bodied to having a SCI. It’s not that easy of a transition and if this could help other people with their transition then I want to be involved.

SCI Access: What kind of studies have you been in?

Randy: I’ve been in a lot of them! I did a study with Dr. Meade recently. It’s about coping with your SCI to the best of your ability.

There was the saliva study. That was the most intense one. They call you at random times and you had to write down what you were doing like shopping or exercising and within a certain time, you have to put a piece of cotton with lemon in your mouth so that it would absorb your saliva. Then you put it in a tube and keep it safe and label it so they could coincide the time and what you’re doing. You had to pay attention!

SCI Access: What has been your experience with the people you’ve met through the Registry?

Randy: It’s always pleasant people calling. It’s not like their telemarketers! Dr. Meade was my psychologist when I had my injury in 1999. Someone did a presentation at the CIL for SCI and I saw Dr. Meade there and I hadn’t seen her in ten years! Then her study came up and that was kind of fun.

I’m not a PhD, but I have a degree in SCI. They’re all brainiacs, but I am living the life so I know what it’s like.

SCI Access: What has the Registry meant to you?

Randy: The studies work on problems that people with SCI are having – both the physical part and the mental part. So the fact that researchers are gathering that information and know how we feel and using that to try to help gives me a good feeling. There’s people
trying to make things better, that’s what the Registry means to me. I still feel committed. As long as I can do studies and I’m eligible, I’ll do ‘em.

SCI Access: What do you hope the Registry will help to do some day?

Randy: Maybe they’ll write a new book on SCI, find different ways of doing things or new therapies, or come out with information for the general SCI public that hasn’t been discovered yet. Finding the cure is what we all hope will happen but in the meantime, let’s keep doing these studies.

SCI Access: What would you say to others about the Registry?

Randy: To join because they do pay ya, there is that! Take your wife out to dinner.

SCI Access: Any final thoughts for those thinking about joining?

Randy has truly proven himself a Registry Super Subject over the past 8 years, exemplifying the giving spirit that makes research work. A big thank you to Randy!

More about the Registry

If you would like to become a member of the Registry, you can join online (www.tinyurl.com/scireg) or by contacting the Registry coordinator, Ms. Rachel Hartwig by phone (734-763-9773) or e-mail (SCIRegistry@umich.edu). Enrollment will take less than 10 minutes.

Thanks to ALL of Our Registry Members!

We would also like to extend our heartfelt appreciation to ALL of our Registry members. You make the wheels go round. We are honored to be your partner as we work together to better the lives of individuals with SCI.

PARTICIPANTS NEEDED

The University of Michigan is conducting a survey study to learn more about bowel and bladder management and complications and their effect on quality of life among people with a spinal cord injury.

In order to participate, you must:

• Be at least 18 years old
• Have had a spinal cord injury for at least five years with associated changes to your bowel and/or bladder functioning
• Receive treatment for your SCI from the University of Michigan Health System or agree to make your medical records available
• Be willing to participate in an interview that will take approximately 1 - 2 hours

If you are eligible and participate, you will be compensated $20.

For more information, call our research office at 734-763-0971

IRBMED# HUM0005879
Principal Investigator: Denise Tate, PhD, ABPP
Medical Director: Anthony Chiodo, MD
Physical Medicine and Rehabilitation
Alumni News
By: Constance Pines, RN

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.

Zina Hermez
Age: 35
Date of Injury: October 18, 1994
Level of injury: L1-L2

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

Zina: While crossing the street on my way to school at sixteen years old, I was hit by a car. My life changed forever. My spine broke at the L1-L2 level. I also had a fracture in my C1 vertebrae with a broken left femur, broken right tib fib, and a broken left tib fib. I was paralyzed. And that wasn’t even all of my injuries.

Eighteen years have gone by, and I taught myself how to walk again. Today I’m walking everywhere with two forearm crutches, and practicing with one cane. I’m up to forty minutes cardio, twenty on the treadmill and twenty on the elliptical. It’s a miracle I’m alive and able to walk. I hope to one day walk with no walking device. I’m grateful to God for how far I’ve come.

I was still able to make it through college in my twenties and earn two degrees. I’ve been in education for over ten years, teaching and tutoring. I’m an English as a Second Language teacher for a Global language training company. I also teach classrooms at a Language center. I’ve enjoyed years of experience tutoring youth. I’m independent, and able to take care of myself.

SCI Access: Share your thoughts and advice? What has kept you motivated since your injury? What have you done to overcome any challenges you have met along the way?

Zina: My advice would be to stay active and exercise, whether in physical therapy or with a trainer. Moving really does improve our health! I believe any movement is good to start. Whether it’s a transfer from your wheelchair to your bed, or using the hand cycling machine in physical therapy, or standing for several minutes at a time in a standing frame, it gets your heart pumping, your blood flowing, and you’re moving. As you train your body to move with help and hopefully eventually without, to sit, to stand, whatever you are able to do, you can become more independent.

It’s also good to stay connected to groups. One year ago I joined an online writers’ group where I met authors. Through classes, webinars, and friendly emails, I’ve been encouraged to write. I started a blog to help cope with my spinal cord injury, in hopes of helping others cope as well. It has been therapeutic, and given me great relief. My hope is that it helps others who visit with or without spinal injury. You can visit my blog here: http://zinahermez.wordpress.com I believe we should never give up on hope for recovery, because it’s never too late to get well. My story has been featured in Christianity Today and Spinalcordinjuryzone.com. I look forward to reaching out more and writing my story to the world!

Handcycling
Continued from page 11

Handcycling can also get you back to an activity that you enjoyed before your injury and/or as a youth. It can give you a very competitive outlet or include you in on a family bike ride. The added strength and cardio workout makes you feel alive and productive. Many people say it transformed their life and even got them eating healthier.

Enjoying the Ride

The best thing about handcycling is that it can be enjoyed by both the young and the young at heart. Handcycling adds a better quality of life for many people with physical disabilities. It offers physical and mental health benefits. After using a handcycle for more than a week you will notice that all of your transferring will become easier. The added strength that it gives to your arms improves your stamina and ability to push your chair longer distances.

through intersections. It is important to be extra safe while out handcycling. Always wear a helmet, have a cell phone and plenty of water with you. When riding alone it is essential to have a six foot safety flag attached to your bike so you are more recognized on the open road.

Enjoying the Ride

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**Accessibility Detroit: Tyree Guyton to Create an Urban Art Project on Disabilities**

By: Lisa Franklin, President, Warriors on Wheels of Metropolitan Detroit

“Disability is not a ‘brave struggle’ or courage in the face of adversity. Disability is an art. It’s an ingenious way to live.” –Neil Marcus, writer, actor, dancer

**The Heidelberg Project** is a constantly evolving outdoor art project in Detroit’s Eastside that was created by internationally known and respected urban environmental artist Tyree Guyton. Through his art, Tyree has transformed his neighborhood into a living indoor/outdoor art gallery where visitors re-imagine what art is and what it means to be human in community. Thousands of people from around the world visit this work of art each year.

Now, working with Detroit’s Warriors on Wheels (W.O.W.) and other artists, activists, and allies, Tyree Guyton is in the process of creating an art installation on disability which will be unveiled in July 2013 in celebration of the 23rd anniversary of the passage of the Americans with Disabilities Act (ADA). The art installation will be a tower of discarded, un-useable wheelchairs, walkers, crutches, power chairs, ramps, prosthesis, and any and all unusable parts of items used by people with disabilities.

“I strive to be a part of the solution. My experiences have granted me knowledge of how to create art and how to see beauty in everything that exists. . . . When you come to the Heidelberg Project, I want you to think--really think! My art is a medicine for the community. You can’t heal the land until you head the minds of the people.” -Tyree Guyton

**How you can participate:**

Expanding his work to include disability is a joyful and thrilling important adventure for ALL of us. Items are needed immediately to begin the create process of building the installation. If you have any items, big or small, you can drop them off at the Heidelberg Project, 3600 Heidelberg, Detroit, MI 48207; leave them on the porch of the “Polka Dot House” Exhibit. The items will not be returned. If you need items to be picked up, contact Lisa Franklin of W.O.W. lfranklinwowlinc@yahoo.com or 313-778-9170; or Rich Feldman of the Boggs Center richardfelman60@gmail.com.

**The Heidelberg Project** is a powerful place to call attention to the disability justice community. For more information about Tyree and the Heidelberg Project: www.tyreeguyton.com and www.heidelberg.org.

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**Exercise and Physical Activity After SCI** Continued from page 5

**Recommendations and Conclusions**

In summary, SCI can alter the function of almost every organ system in the body. Exercise has the potential to limit or prevent decline and to improve functioning of each of these systems as well of the body as a whole. Exercise may also help prevent many of the common chronic diseases and secondary health problems that occur after SCI, and perhaps most importantly, may promote a higher level of physical fitness and a corresponding higher level of functional independence. Ultimately, exercise participation can help build psychosocial well-being and lead to an overall improved quality of life.

That said, physical activity and exercise are not without risks and the potential for injury. The exact type of risk may be specific to the type of activity or may depend on level and completeness of SCI. Thus, it is important to talk with your physician prior to starting a new exercise program of if you are experiencing pain or concern for injury.

**Resources**

For more information about the types of physical activity and exercise that may be open to you, talk to your physician or physical therapist. Centers for Independent Living and peers with SCI also can serve as great resources for identifying accessible fitness facilities and other resources in your area. Other resources available related to physical activity and exercise for individuals with disabilities include:

The National Center on Health, Physical Activity, and Disability (NCHPAD) provides information on adaptive physical activities as well as exercise options. Find out more at http://www.ncpad.org/ or by contacting their staff via phone (1-800-900-8086) or email (email@ncpad.org).

The North Carolina Office on Disability and Health offers the brochure, Removing Barriers to Health Clubs and Fitness Facilities: A Guide for Accommodating All Members, Including People with Disabilities and Older Adults, as well as a wealth of other resources. Find these online at http://projects.fpg.unc.edu/~ncodh/PhysicalActRec/index.cfm

Finally, the Michigan Disability Health program may be able to provide information. See their website (http://www.michigan.gov/mdch/0,1607,7-132-2940_2955_54051---,00.html) or contact: Candice Lee, Program Coordinator (517-335-3188 or LeeC@Michigan.gov).
New SCI Support Group at MedRehab

The Spinal Cord Injury Program at the University of Michigan is pleased to announce that we have started hosting a monthly SCI Support group. It is facilitated by Ms. Darlene Klien, Case Manager and family therapist at MedRehab, and Dr. Nancy Merbitz, Rehabilitation Psychologist at University Hospital and MedRehab. Participation is free and open to individuals with spinal cord dysfunction, including those with SCI and multiple sclerosis, and their family members. The commonality is that all participants have had their day to day lives altered by difficulties with strength, mobility, and other neurological functions.

As described by Dr. Merbitz, “the group is a way to bring people together who are dealing with spinal cord problems.” As a support group, the agenda and focus are being developed by the people who attend. Among the issues that have been brought up so far are:
- “figuring out how to do stuff for myself”
- finding transportation (including public transportation)
- hopes and disappointments and new hopes
- how to pursue hobbies, education, and/or employment in spite of barriers

The group meets at MedRehab from noon until 1 pm on the last Tuesday of every month. A light snack is provided, or participants should feel free to bring their lunch.

For more information, contact Ms. Darlene Klien (734-998-8096). Many good ideas are being shared, and there is room for more. We would love to meet you!

Upcoming Meetings At Med Rehab
355 Briarwood Circle, Building #4
Ann Arbor, MI 48108
Noon to 1pm
May 28th
June 25th
July 30th
August 27th
September 24th