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MS VETERAN

SERVING THE HEALTH CARE NEEDS OF VETERANS WITH MS

LET THE VA WHEELCHAIR GAMES BEGIN

MICHAEL LOTOCKI - RIVER VALE, NJ: This year was my first time attending the Wheelchair Games. It was also my first time participating in the shot put and discus throw competition. This experience was truly wonderful and refreshingly new. The games were a wonderful place to come out, participate, integrate into society, and meet fellow Veterans from all over the nation with similar disabilities. I feel the games are not just about competition, that is the last thing the games are about. Everyone that shows up for the games is a winner because they got out of bed and did not cry “woe is me.” They decided to live life to the fullest and that’s what the games are about!

I know that I would not have had the strength and ability to prepare for the games without the care and support of the wonderful spinal cord injury and disorders (SCI/D) and recreation therapy staff at the East Orange, NJ VAMC. After being cleared by the SCI/D Chief, weight training was used to help me and other Veterans regain whatever functions in our bodies we could. I don’t have use of one of my arms. Through the weight training I increased the use of my hand and continue to see



improvements. The weight training has made a major difference in my daily functioning. I can now perform simple tasks again such as opening containers, bathing, and now the games!

Recreation therapy has helped me and other Veterans in amazing ways. The improvement in my quality of life and independence cannot be overstated. The East Orange VAMC SCI/D and recreation therapy programs have made a major difference in my life and the lives of many other Veterans with MS and SCI/D. They are truly caring professionals and it is obvious that they put Veterans first. My participation in this year’s games is one of many positive results I have experienced and I commend the East Orange VAMC staff and organizers of the wheelchair games for this exciting opportunity.

JANET MOYER - ZION GROVE, PA: I served in the US Navy and I have MS. I had first heard of the Wheelchair Games through other Veterans while at the East Orange, NJ VAMC for my annual visit. The Veterans were talking about how much fun they were having and that you compete

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with other Veterans. I inquired about the games with my doctor and the Recreational Director and was encouraged to go to next year's games.

My first experience with the games was in 2008 in Omaha, NE. I was both nervous and excited. Upon my arrival, the number of volunteers was amazing and they all went out of their way to help each Veteran. I also could not believe how many Veterans were there with all kinds of disabilities. Some had MS, some were amputees, some were quadriplegics, but all were in high spirits and ready to go!

On the day of check-in I was evaluated to determine my strengths and weaknesses to see what classification I would fall under for competition. I competed in two field events, bowling and weightlifting, and one track event. I came home with two gold medals and one silver. I was so proud that I accomplished that. I watched all the different events and decided what I would compete in for next year's games. Having MS, I realized that certain events are harder than others for me, but nothing was going to stop me from trying.

In 2009, the games were in Spokane, WA. The temperature outside was in the high 90's the day of the field events. Participants with MS knew that we needed to stay out of the heat and I made sure I had a hat covering my head and I kept putting cold towels around my neck. I rested when I could so that I would not wear myself down to the point of an exacerbation.

This year, the games celebrated its 30th year in Denver, CO and I was proud to participate. The weather was beautiful and we received commemorative rings in honor of the 30th anniversary. I tried a new sport to compete in, the motorized slalom, which is an obstacle course

where you go around cones, up and down a small ramp, and through doors that have cones on top. You cannot tip any of the cones over! It was a lot of fun and I'll compete in that sport again next year in Pittsburgh, PA. My family will be joining me next year which will be wonderful.

The games remind me of summer camp, where you look forward to that one week a year where you get to see the people you became friends with from prior years and meet new ones just beginning to compete. Having MS has slowed me down some, but there are wonderful people out there to help and the feeling of accomplishment I get is wonderful!

JULIE ADAMS, CTRS - SEATTLE, WA: I am a certified therapeutic recreation specialist at the Puget Sound Health Care System. I have attended the games as a coach for four years. To see the dedication and drive of over 550 wheelchair athletes never ceases to amaze and inspire me. These men and women not only made the ultimate sacrifice by defending our country, but have overcome obstacles in order to participate in something athletic, meaningful, and rewarding.

The National Veterans Wheelchair Games are the largest wheelchair sporting event of its kind in the world. This week long competition is hosted by the VA and the Paralyzed Veterans of America, and co-sponsored by various committed organizations and companies. The games are held in a different city each year and participating athletes choose from over sixteen different events to compete in, including power soccer, table tennis, hand-cycling, bowling, softball, basketball, quad rugby, swimming, track and field, motor rally, slalom, air guns, archery, and weightlifting.

Veterans who use a wheelchair to participate in leisure or recreational activities are eligible to participate. No previous athletic experience is required and financial support is available. All Veterans need is the willingness to try something new and the dedication to make it happen.



Veterans are typically evaluated by a recreation therapist to determine the appropriateness and commitment needed to participate in the games. At the Puget Sound VAMC, once Veterans are determined to be eligible, medically stable, and they demonstrate appropriate goals and motivation, they become part of our team and the training begins!

After months of training to prepare for the competition our team heads to the games. Upon arrival, each athlete is required to register which involves classifying each Veteran's level of athletic participation. The classification process ensures that Veterans of similar abilities safely compete in each event. On the night of registration, athletes participate in opening ceremonies, complete with a parade of athletes, lighting of the torch, and entertainment!

Throughout the week, athletes participate in individual events. Gold, silver, and bronze medals are awarded following the completion of each event. On days that Veterans are not competing, athletes have the opportunity to do local sightseeing and are encouraged to support other athletes as spectators. At the end of the week, there are closing ceremonies, which consist of a banquet dinner, special awards, the passing of the torch, and the much anticipated video highlights of the games.

Most Veterans find that participating in the games gives them something to look forward to, a sense of purpose and drive. For some it has been a long time since they have felt this way. The opportunity shows people how to get back into an active lifestyle focusing on "abilities" and NOT "disabilities." Most have a life changing experience and a desire to return the following year.

KEEP MOVING FORWARD: AVOIDING FALLS

Because MS can affect any part of the brain or spinal cord, it can cause different problems for each person. Many people with MS have poor balance, problems with walking, and are at risk for falling. Research is helping scientists find out how to help people with MS improve their balance and walking and fall less.

Imbalance is one of the most common symptoms of MS. People with MS often say they feel off balance and researchers have found three types of balance problems in people with MS. First, most people with MS sway more than they should when they try to stand still. They also increase this swaying more than expected when they close their eyes or reduce their base of support by standing on one leg or with feet together. Second, when leaning, reaching, or stepping, people with MS cannot go as far or move as quickly as they normally should. Third, people with MS have difficulty controlling their

balance when pushed or pulled.

Walking problems are also common in people with MS. They tend to walk more slowly than other people, take shorter and slower steps, and their joints move less when they walk. Their

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walking gets even slower when performing a mental task, like walking through a store while looking at things on the shelves, talking, or trying to remember a grocery list. They also use more energy to walk.

Walking problems in people with MS are related in part to problems with balance. Walking requires people to maintain their balance when standing on one leg, then leaning forward, and then using the other leg to catch themselves. Poor balance can interfere with standing, particularly on one leg, as well as leaning.

People with MS fall frequently and often fall badly enough to be injured. Some people with MS are so afraid of falling that they stop being active to avoid falls. People with MS also say they fall more if they try to pay attention to too many things at once or if they get fatigued or overheated. Falls in people with MS are associated with poor balance and reduced ability to walk.

Scientists are trying to develop effective treatments for imbalance, walking difficulties, and fall prevention in people with MS. Recent research suggests that imbalance and walking problems are caused by slowed transmission of the sensation of where one's body parts are. To keep your balance, or step and land where you



want to without looking down, you need to be able to feel where your feet are, quickly. When this information reaches the brain too slowly, people have worse balance. Their brains don't know where their feet are quickly enough to put them in the right place. This makes them unsteady, walk slowly, and be more likely to fall.

A number of things can improve balance and walking and reduce the risk of falls in people with MS. We know that exercise, modifying how one does things, and various devices can all help. Exercising in a standing position with gradually increasing balance challenges, such as Tai Chi, can be particularly helpful.

Modifications that are helpful include minimizing distractions while walking and removing hazards. Avoid standing or walking when doing difficult mental tasks. Going to the store at less busy times and removing rugs and cords you could trip over at home. Using canes or hiking poles, well fitting lace up shoes, leg braces, or elastic straps on the legs, all of which give your brain more information about where your legs and feet are, can also be helpful.

More research is needed to know what works best, but for now, people with MS should get help from their doctor and a physical therapist to choose the best strategies for them to improve their balance and walking and to reduce their risk of falling.

Carolyn Bacon - Pomona College

Michelle Cameron, MD, PT - Portland VAMC

FINGOLIMOD: A NEW TREATMENT FOR MS

In June 2010, a US Food and Drug Administration (FDA) advisory panel unanimously recommended the approval of fingolimod (Gilenya®) 0.5 mg/day as a new treatment for relapsing-remitting MS and on September 22, 2010, it was given FDA approval for use in the

US. Fingolimod, also known as FTY720, is an oral agent that has been shown to prevent MS attacks, also known as relapses or exacerbations. It has also been shown to reduce the appearance of brain lesions on MRI, evidence of disease activity. When approved, fingolimod became the first pill with disease modifying activity approved for the treatment of MS.

Fingolimod should not be confused with

dalfampridine (Ampyra®), a different “MS pill” that was approved by the FDA earlier this year. Dalfampridine helps to manage symptoms by allowing some MS patients to walk better, but it does not modify MS disease activity. Fingolimod, in contrast, actually alters the course of the MS disease process, preventing MS attacks and reducing the number of MRI brain lesions.

Fingolimod is the first drug in a new class of compounds that affect sphingosine-1-phosphate receptors, proteins on the surface of white blood cells that are important in their movement in the body. Fingolimod is derived from myriocin, a natural antibiotic and immunosuppressant compound produced by a fungus called *Isaria sinclairii*. According to traditional Chinese medicine, this fungus was believed to promote eternal youth.

Fingolimod appears to reduce MS activity by trapping white blood cells, part of the body’s defense against disease and foreign materials, in the lymph nodes. This prevents white blood cells from entering the brain and spinal cord and causing damage. In two different phase III clinical trials (FREEDOMS and TRANSFORMS), involving almost 2,500 patients, fingolimod reduced relapses by more than 50% when compared to beta interferon-1a (a standard MS treatment) or a placebo, essentially cutting the number of MS attacks in half. Fingolimod also appears to reduce disability progression over time by about one third.

According to both studies, fingolimod was generally safe and well-tolerated. Side-effects associated with fingolimod include cardiac changes, a minimal increase in blood pressure, reversible blurred vision, and a mild increase in liver enzymes in the blood (an indication of subclinical liver damage). Most of these side-effects were symptomless and resolved after fingolimod was stopped.

More serious adverse events associated with

fingolimod included a slightly increased incidence of lung infections (bronchitis or pneumonia) and two deaths that occurred in patients receiving high-dose fingolimod, 1.25 mg/day instead of 0.5 mg/day. Both deaths were due to viral infections; one patient died of herpes simplex encephalitis and the other died of disseminated herpes zoster. The exact relationship between fingolimod and serious viral infections is not known, particularly with the lower (0.5 mg/day) dose of fingolimod.

Despite safety concerns, the approval of fingolimod was highly anticipated by patients and physicians, both because of its apparent effectiveness in battling MS and because many patients were looking forward to being able to treat MS with a pill instead of a needle. There are currently seven other medications that have been FDA-approved for the treatment of MS, including two brands of beta interferon-1b (Betaseron®, Extavia®), two forms of beta interferon-1a (Avonex®, Rebif®), glatiramer acetate (Copaxone®), mitoxantrone (Novantrone®), and natalizumab (Tysabri®). All of these medications, however, must be given by needle injection under the skin, in the muscle, or into a vein and may be associated with side-effects that may limit their use in some patients.

Other “MS pills” on the horizon include oral cladribine (Mylinax®), laquinimod, and BG-12, all of which have done well in clinical studies and have been granted “fast track” status for approval by the FDA. Veterans with MS who are interested in fingolimod treatment should discuss the risks and benefits with their health care provider.

Robert Shin, MD - Baltimore VAMC

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MS World is an on-line organization run by volunteers with MS who are committed to helping others with MS seek the best quality of life possible.

EXERCISE AND MS

Q: I have mild MS. I occasionally get very tired after short walks or brief activities. I have nearly fallen a couple times and once was very embarrassed because I knocked a bag of groceries out of a fellow shopper's hands when I tripped. How can I decrease my fatigue and improve my walking? Jim R., age 43

A: First of all, Jim should be congratulated for taking an active approach to managing his MS symptoms. Learning the best way to exercise after developing a life-changing disease like MS can be challenging, but important. The first step to finding solutions is to seek information.

Jim describes two different but often related MS symptoms - weakness and fatigue. Leg weakness usually means that you are using more energy to walk and do everyday activities. Using more energy to move around just doing everyday activities often contributes to a feeling of fatigue.

Regular exercise is one of several steps needed to help manage fatigue. However, the difficulty walking that Jim describes means that running, walking, or working out on a treadmill are not the best exercise choices. A safe exercise program would be using an exercise bicycle or water exercising in a pool. Jim may also do well using an elliptical trainer - machines where the foot is not lifted with each cycle of the foot pedals.

It is generally recommended that people should exercise aerobically three to five times a week. This includes people with MS. The duration of exercise should be twenty minutes or more each day. Because Jim suffers from fatigue, starting out exercising twenty minutes per day may not be very realistic or possible. He should start with what he can do, build on his success, and then slowly increase his exercise time. His plan should be to start with three to four minutes, next increase from four to five minutes, and then from five to seven minutes, etc. Jim can remain at those

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periods for as long as he needs to until he's ready to go up to the next level. An alternate approach would be to do two five to ten minute sessions.

Jim may wonder how hard he should exercise. The "gold standard" is for him to monitor his heart rate, but this does not always work for people with MS. Jim may find that MS causes numbness and tingling in his fingers and it is hard to feel a heart rate. If this is an issue, it's recommended that he exercise to a level where a conversation can be held while still exercising. He should be cautious of overheating and keeping a water spray bottle handy to spritz himself or exercising in a cool room is recommended.

Once Jim gets the right kind of exercise program he should look for ways to decrease the amount of energy he uses in daily activities. Separating exercise from daily functional activities is an important step in reducing fatigue. It is important for Jim to closely look at all his daily activities and become more efficient by learning how to modify them to decrease the amount of energy they require. Many people have found an activity diary to be a very useful tool. If Jim kept an activity diary for three to four days in a row, he

may start to see patterns of what he is doing. Once he sees these patterns, he can change his activities so during times of energy, he can do activities that require energy and during low energy times, he can do things that do not take a lot of energy.

If Jim has difficulty identifying how to change activities to be more efficient or finding the right exercise program, he could talk to his doctor about referrals to physical and occupational therapists. Physical therapists are experts at

identifying causes and solutions for walking problems and helping people find the right exercise program. Occupational therapists are experts at modifying everyday activities to increase safety and efficiency.

The VA has a wonderful system of health care providers that are available. Talk with your health care provider about seeing therapists that can help you live fully and meaningfully with MS.

Cinda Hugos, MS, PT - Oregon Health Science U

CARING FOR THE CAREGIVER

Dedicating time, energy, and emotional commitment to another person can be fulfilling in so many ways. For many, being a caregiver provides richness in life and an expression of love for the person who needs assistance. Yet, the physical, mental, and emotional demands of care giving are great and this can sometimes lead to fatigue, stress, and feelings of depression, what many refer to as caregiver burnout. For caregivers to avoid burnout, it is vital that they be aware of their own limitations and learn to care for themselves.

It may be difficult for caregivers to recognize burnout in themselves. Often others around caregivers may notice changes that are not easily recognized by the caregivers themselves. Some of these symptoms may include depression, a sense of helplessness or hopelessness, constant exhaustion, changes in eating or sleeping patterns, withdrawal from social supports and activities, anxiety, feelings of resentment, and increased use of medications, alcohol, tobacco, and other substances. Caregivers may experience all or some of these symptoms. The good news is that there are strategies to help avoid caregiver burnout.

An important first step is to acknowledge that once someone is a caregiver, they have the potential for burnout. With this acknowledgement, caregivers can then take steps

to prevent or relieve burnout. There are several ways this can be achieved.

SUPPORT SYSTEMS: Support systems can include family, friends, other caregivers, health care professionals, specialty organizations, church members, and others. It is important to share thoughts and feelings with others. Some particular outlets for this can be through support groups, professional counseling, or the simple act of sharing with family and friends about the joys and tribulations of care giving. It may be important for some caregivers to also maintain their spiritual health and support. Support from others can be the most important defense against burnout.

RESPIRE CARE: Everyone needs a break from time to time and caregivers especially need this time for rest and rejuvenation. Respite care typically means that caregivers get a break by having someone else take over the care giving responsibilities for a period of time. Family, friends, and certain professional agencies can provide this service through in-home assistance, adult day health, and community nursing facilities. Some Veterans are eligible to receive respite care for up to 30 days in a calendar year through the VA. Several chapters of the National MS Society provide respite care through their care management and financial assistance programs.

EXERCISE AND DIET: As with any positive health approach, one way to stay healthy is to

exercise regularly, practice healthy eating, and get plenty of sleep. Exercise can also provide time alone to refresh the body and the mind.

ESTABLISH PERSONAL TIME: Personal time can be quite difficult to arrange and some caregivers may feel guilty if they spend time on themselves and not their loved ones. However, it is essential for caregivers to take time for themselves - one cannot be a caregiver 24/7. This personal time can include short walks, reading, listening to music, meditating, staying involved in hobbies, and doing whatever the caregiver's personal interests may be.

SIMPLIFY: Making the home environment as user friendly and accessible as possible and taking advantage of assistive technology can make life easier. There are several programs and grants available through the VA to make medically necessary home improvements. Some

of these include the Specially Adaptive Housing Grant, Home Improvements and Structural Alterations Program, Special Housing Adaptions Grant, and Temporary Residence Adaption Grant. Based upon each Veteran's medical needs and eligibility, wheelchairs, sports chairs, and scooters are also available through the VA. Information on these benefits can be found at www.vba.va.gov/VBA.

Care giving is a difficult undertaking. It is a journey that should not be made alone. Support is crucial and there are many avenues to obtain this support. If caregivers neglect themselves, they cannot provide proper care to others. If you are a caregiver, reach out to others, do not hesitate to accept help from others, and remember that your mental and physical health are as important as your care giving responsibilities!

James Shepard, LICSW - Puget Sound HCS

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