The goal of MS rehabilitation therapy is to maintain or improve function in those who may be struggling with disability. As is the case with MS disease-modifying therapies, rehabilitation doesn’t stop the progression of the disease, but it has many benefits and can greatly improve an individual’s quality of life. Rehabilitation offers non-drug approaches for treatment however it should be used alongside the MS medications. Rehabilitation specialists can provide education and strategies to address or prevent many complications of MS, such as decreased mobility and independence, fatigue, trouble swallowing, or problems with thinking and memory (to name a few). Rehabilitation is especially important after a flare to recover as much of one’s ability as possible. Read more about this essential component of MS care.

Rehabilitation begins with a baseline evaluation of how a person is functioning, both physically and mentally. A treatment plan can then be determined based on an individual's needs. Rehabilitation professionals use a wide variety of standardized tests to determine how a client is doing. Throughout treatment, these evaluations must be performed periodically to measure the treatment’s effectiveness, allowing the treatment regimen to be adjusted, if needed. Learn more about the assessments a physical or occupational therapist may ask an individual with MS to complete.
Functioning better and feeling productive adds enormously to the quality of life of people with MS and their families. Rehabilitation is more than an “extra” therapy that is given after other medical treatments. It is an integral part of managing and treating the diverse set of issues often encountered throughout the course of MS. As such, learning more about and improving therapeutic techniques is of vital importance to those living with the disease so they can live their best life every day. Our third article covers some of the ways MS researchers are working to better understand the underlying causes for disability and improve rehabilitation techniques and programs.

Our Research Spotlight contains opportunities to participate in studies, MS events, as well as recent research results. This month we feature an exercise behavior study at the University of Alabama at Birmingham and REAL MS, a longitudinal study of MS. Also featured are a concert to benefit ACP and MS research by the popular Chicago band, Lucky Boys Confusion, and a webinar intended to dispel the myths people often have about participating in MS research. In addition, a new treatment for relapsing forms of MS was recently approved and will be available in the United States in the near future. Click here to learn more!

**Rehabilitation Therapy – Better Living with MS**

The goal of MS rehabilitation therapy is to maintain or improve function in those who may be struggling with disability. It is an essential component of MS care. As is the case with MS disease-modifying therapies, rehabilitation doesn’t stop the progression of the disease, but it has many benefits and can greatly improve an individual’s quality of life. Rehabilitation offers non-drug approaches for treatment however it should be used alongside the MS medications. Rehabilitation specialists can provide education and strategies to address or prevent many complications of MS, such as decreased mobility and independence, fatigue, pain, bladder or bowel dysfunction, trouble swallowing, impaired communication, or problems with thinking and memory (to name a few). Rehabilitation is especially important after a flare to recover as much of one’s ability as possible. Depending on symptoms, an individual may only occasionally need rehabilitation therapy
or they may require it regularly. In either case, it's important to consider it for MS as early as possible as this can make a big difference in its effectiveness.

Rehabilitation therapy for MS is multidisciplinary, which means it involves multiple specialties working together as needed. Physical therapy (PT) focuses on treating the muscles and tissues of the body to maximize function, mobility and safety. This usually involves doing targeted exercises to build strength in a specific area. Exercises may be aimed at improving one’s posture, balance and gait, conserving energy and reducing fatigue, stretching tight muscles, increasing manual dexterity or minimizing pain. It can also include pelvic floor exercises to address urinary/bladder issues. Some programs offer at-home exercises that people with MS can do on their own to maintain progress. As mentioned in our June 2019 newsletter, mobility aids may be useful tools to help people with MS be more ambulatory and active. PT might include choosing and fitting these devices, and training in their use. As heat is often a trigger that worsens MS symptoms, a physical therapist can provide advice on cooling products that may help in this regard. It’s important to keep in mind that individuals with MS should see a physical therapist that specializes in neurological conditions, rather than orthopedic conditions. They have expertise in treating people with movement disorders due to a disease of the nervous system, like MS.

Occupational therapy (OT) often complements PT. It is intended to help individuals complete “activities of daily living”, which are defined as six basic tasks: eating, bathing, dressing, toileting, walking/transferring, and continence. It can also include other things, such as leisure activities and work. While a PT works on building strength and flexibility, OT often works on finding easier ways of doing things by breaking down tasks into their components and helping people with whatever aspects are problematic. These professionals may employ a variety of techniques, ranging from muscle strengthening to energy conservation. An occupational therapist may visit a client’s home to ensure that it’s safe and accessible to accommodate their limitations (and recommend modifications if it’s not). If needed, they can offer advice and training on aids or devices that may be helpful in completing daily activities. An occupational therapist can also help individuals figure out when they have the most energy and focus, so they can plan their day in a way
that makes them the most productive. Some also evaluate and treat problems with thinking and memory.

Just as people with MS may lose control over some of the muscles involved in walking, some lose control over muscles that control speech. Speech therapy, typically provided by a speech and language pathologist (SLP), can help to retrain these muscles, which will help make speech clearer. This training may also improve swallowing ability, since swallowing involves many of the same muscles used for speaking. A SLP can teach their clients exercises to help improve breath support. In addition, they can provide information and advice regarding devices that can help one interact, such as voice amplification devices, or computer-assisted communications devices. Their goal is to make communication easier and clearer, as well as promote safe swallowing and overall health. Like occupational therapists, some SLPs also evaluate and treat problems with thinking and memory.

As discussed in our June 2019 newsletter, up to 65% of people with MS have problems with aspects of thinking at some point in the course of their disease. This might include difficulty with memory, concentration, organization, problem solving or multitasking. Cognitive therapy offers strategies that may help with these issues. For example, it might include learning to use a smartphone to set reminders, or training to manage more than one task at a time. A number of professionals evaluate and treat these symptoms, including neuropsychologists, OTs and SLPs. While each of these specialties uses different evaluation and treatment strategies, they share the common goal of helping people with MS function better if cognitive changes are an issue.

Counseling plays an important role in rehabilitation therapy for people with MS, caregivers and family members, alike. There’s a huge emotional component to living with the disease. Feelings of loss, fear of change or uncertainty about the future are not uncommon. It’s important not to face these feelings alone. Individual counseling or participating in a local MS support group can offer effective coping strategies and fellowship. The National MS Society has a number of resources to help individuals with
MS get the emotional and social support that they need to work through these difficult feelings.

People with MS frequently must overcome physical, mental and emotional challenges in order to accomplish daily tasks and achieve long term goals. Living the best life possible with the disease requires perseverance and a commitment to developing new ways of doing things. It’s important for people with MS to assemble a healthcare team that includes rehabilitation professionals, when necessary. MS is unpredictable and affects everyone differently. The rehab team can look for and identify problems, set goals, and come up with individualized solutions to maximize function and quality of life. It’s important to keep in mind that it may take time to see results from rehabilitation therapy and there may be frustrations along the way. However, many people with MS find it to be effective at reducing any loss of mobility or function they may be experiencing, and the long-term benefits are well worth it.

How are you functioning with MS?

The goal of rehabilitation therapy for MS is to reduce disability and help those living with the disease continue to live as independently as possible with the abilities they have. Rehabilitation begins with a baseline evaluation of how a person is functioning, both physically and mentally. A treatment plan can then be determined based on an individual's needs. Rehabilitation professionals use a wide variety of standardized tests to determine how a client is doing. These assessments measure changes in health status (also known as health outcomes). Throughout treatment, these evaluations must be performed periodically to measure treatment effectiveness, allowing for the treatment regimen to be adjusted, if needed. As discussed in our
health outcomes are classified according to the source from which they are collected. A physician reported outcome is one collected by a physician in the course of clinical care (for example, the physical exam or lab tests). A patient reported outcome (PRO) is one directly reported by the patient who experienced it. Both points of view are very important because they measure different components of a person’s wellbeing. MS rehabilitation therapy uses both types of health outcomes to determine a patient’s functional status and to provide the individualized treatment someone living with the disease requires.

Many people with MS experience difficulty with walking. A number of tools are specifically intended to evaluate an individual’s gait. Physical and occupational therapists rely on the information obtained from these instruments in their work. They may also gather information about an individual’s home and working environment, as well as their usual activities. These details give them insight for any recommendations they may have.

**Gait assessments**

A [functional gait assessment](#) (also known as dynamic gait index) evaluates not only an individual’s usual gait, but also walking during more challenging tasks. After walking at their normal speed for 20 feet, individuals are presented with different challenges while walking, such as walking at different speeds, turning and nodding their head, pivoting and stopping, walking over and around obstacles, as well as up and down stairs.

The [6-minute walk test](#) measures the distance an individual is able to walk over a period of 6 minutes on a hard, flat surface. The goal is to walk as far as possible. The person is allowed to walk at their own pace and rest as needed during the test.

The [Timed 25 Foot Walk](#) (T25-FW) measures the amount of time it takes a person to walk a clearly marked 25-foot course as quickly and safely as possible. Upon completing the task, they must walk back the same distance in the same manner. Individuals may use assistive devices while walking. The evaluator records the amount of time it takes to complete both passes.

The [Hauser Ambulation Index](#) is similar to the T25-FW. The patient is asked to walk a distance of 25 feet as quickly and safely as possible and is allowed to use mobility aids. The examiner
records the time and type of assistance needed, if any. Scores range from 0 (asymptomatic and fully active) to 10 (bedridden).

The Rivermead Mobility Index (RMI) is a tool that combines the patient and clinician perspective to assess gait, balance and transfers. It is a survey with 15 questions related to mobility in bed, transfers, walking, stair use and running. The examiner is required to make one observation, which is whether or not the patient can stand unsupported for more than 10 seconds. All items are answered in a yes/no format with positive responses scoring a 1 for a maximum score of 15.

The 12-Item MS Walking Scale is a PRO that captures the patient perspective on the impact of MS on the individual's walking ability.

MS can affect an individual’s balance in a number of ways both directly, as a result of nerve damage, and indirectly from the impact of other MS symptoms (such as vision or sensory issues). Instability can affect many aspects of daily life, including walking ability. The following assessments are the first step to building a rehab treatment plan to improve this troubling MS symptom.

Balance Assessments

The Activities-Specific Balance Confidence Scale is a self-reported assessment of a person’s degree of confidence in performing various activities without losing balance or experiencing a sense of unsteadiness.

The Dizziness Handicap Inventory is a 25-item PRO instrument measuring the functional, emotional, and physical effects of dizziness and unsteadiness. The patient is asked to answer each question as it pertains to any issues they may have experienced over the past month.

The Berg Balance scale is a widely used clinical test comprised of a set of 14 simple balance-related tasks, ranging from standing up from a sitting position, to standing on one foot. It does not include an assessment of gait.
The **Four Square Step Test** is a clinical assessment of a person’s ability to step over objects forward, sideways, and backward. Two canes are placed in a cross configuration on the ground, creating four quadrants. An evaluator measures the amount of time it takes a patient to step sequentially from quadrant to quadrant, facing forward, both clockwise and counterclockwise. Those unable to face forward during the entire sequence may turn before stepping into the next square.

The **Timed Up & Go** test measures the time taken by an individual to stand up from a standard arm chair, walk a distance of three meters (approximately 10 feet), turn, walk back to the chair, and sit down. Subjects can wear their regular footwear and use their customary walking aid. No physical assistance is given.

The **Tinetti Assessment Tool** measures a person’s gait and balance. The test is scored on their ability to perform specific tasks, including rising from and sitting down in an armless chair, standing, turning and walking. During this test, individuals can use any assistive devices they would normally use.

The **Trunk Impairment Scale** assesses balance and trunk coordination in a sitting position. This includes the ability of an individual to maintain a sitting position while crossing their legs, rotating and bending their trunk from side to side, and lifting each hip.

The **Functional Reach test** assesses a person’s stability by measuring the maximum distance an individual can reach forward while standing in a fixed position (without taking a step). A modified version allows the individual to sit during the test.

Weakness, which is common in MS, can occur in any part of the body. Weakness in the legs, ankles and feet can interfere with walking. In the upper body and arms, it can interfere with everyday activities and self-care. Rehabilitation professionals can evaluate weakness and implement therapy accordingly to help.
Weakness assessments

The Manual Muscle Test is a widely used test to determine muscle strength and weakness. It assesses the maximum force a muscle is capable of generating.

In cases of hand weakness, physical and occupational therapists often use a hand-held device, such as a dynamometer or a pinch gauge, to evaluate grip strength.

The Five Times Sit to Stand measures functional lower extremity strength. In this timed evaluation, subjects sit in a chair with their arms folded across their chest and are asked to stand up and sit down as quickly as possible five times, keeping their arms folded.

Spasticity (feelings of stiffness or involuntary muscle spasm) is a common symptom of MS. It may be as mild as a feeling of tight muscles, or severe enough to cause painful, uncontrollable spasms of extremities. Although spasticity can occur in any limb, it is most common in the legs. The Modified Ashworth Scale is a measurement standard many rehabilitation specialists refer to for a determination of how much muscle spasm a client may have and how best to treat it. Subjects are asked to lay flat on their back for this assessment. If testing a muscle that primarily flexes a joint, the joint is placed in a maximally flexed position and moved to a position of maximal extension over one second. If testing a muscle that primarily extends a joint, it is placed in a maximally extended position and moved to a position of maximal flexion over one second. The assessment is scored based on the amount of muscle tone and how easily the joint moves.

Many people with MS struggle with a loss of dexterity in their hands. Activities such as picking things up, holding on to items, writing, buttoning clothing, or controlling eating utensils may be very difficult. Listed below are two common ways clinicians may measure hand function.
**Upper extremity assessments**

*9-Hole Peg Test* – The patient is seated at a table with a small, shallow container holding nine pegs and a block with nine empty holes. He or she must pick up the nine pegs one at a time as quickly as possible, put them in the holes, and then remove them as quickly as possible one at a time, replacing them back into the shallow container. The total time to complete the task is recorded. Both the dominant and non-dominant hands are tested twice.

*Box and Blocks Test* (BBT) – Individuals are seated at a table, facing a wooden box divided into two compartments by a partition, one compartment containing 150 blocks. Individuals are asked to move as many blocks as they can, one at a time, from one compartment to the other, within 60 seconds. Typically, both hands are tested, beginning with the unaffected hand. The BBT is scored by counting the number of blocks moved during the one-minute period.

Sensory problems occur in 20 to 50 percent of people with MS and are often one of their earliest symptoms. These abnormal sensations include numbness, tingling, burning and increased sensitivity. The *Semmes-Weinstein Sensory Test* is a device used to map out sensory loss. This tool consists of a set of monofilaments that vary in thickness and diameter. Each one is color coded according to the degree of stimulation it gives. The evaluator gently presses the filament on the individual’s skin, systematically starting with the smallest monofilament (with the least stimulus) and working up to the largest filament. He or she notes the smallest filament the person feels.

According to the National MS Society, 80% of people with MS experience fatigue, and over half rank it as one of their most troubling symptoms. Fatigue can be either physical or cognitive, or both at the same time. Physical fatigue may affect an individual’s energy and motivation. Cognitive fatigue, on the other hand, could affect one’s concentration and memory. In either case, fatigue negatively impacts the functioning and quality of life of the majority of people living with MS. A number of PRO measures are used to assess the level of fatigue an individual may have.
Fatigue PRO assessments

The Fatigue Scale for Motor and Cognitive Functions is a 20-item questionnaire about problems that are directly associated with MS-related physical and cognitive fatigue. Individuals are asked to complete the instrument based on how they feel in normal day-to-day life.

The Modified Fatigue Impact Scale contains 21 questions about the effects of fatigue over the last month. The total score is the sum of the scores for each question. Individual subscale scores for physical, cognitive and psychosocial functioning can also be generated by calculating the sum of specific sets of questions.

The Fatigue Visual Analog Scale consists of 18 items relating to the subjective experience of fatigue. Each question is presented as a 10 cm horizontal line that extends between two extremes (“not at all tired” to “extremely tired”). Respondents place an “x”, representing how they currently feel, on the line. The distance along the line is measured and recorded.

Studies suggest up to 65% of people with MS have problems with aspects of thinking, such as memory, concentration or problem solving, at some point in the course of their disease. These difficulties usually develop gradually over time. As we discussed in our March 2019 newsletter, cognitive difficulties can have a big impact on daily life. Clinicians specializing in rehabilitation use a number of tools to determine the degree of cognitive impairment their clients may have.

Cognitive Dysfunction Assessments

The Paced Auditory Serial Addition Test (PASAT) assesses auditory information processing speed and flexibility, as well as calculation ability. Single digit numbers are presented every 2 or 3 seconds and the patient must add each new digit to the one immediately prior to it.

The Perceived Deficits Questionnaire (PDQ) is a 20-question PRO to assess cognitive dysfunction in people with depression. It focuses on everyday situations in which cognitive difficulty may play a role. The PDQ generates a total score and four individual scores for different cognitive skills – attention/concentration, memory and planning/organization.
MS reduces quality of life (QOL) by interfering with the ability to work, socialize and participate in daily activities. The goal of MS rehabilitation therapy is to maximize QOL for all living with the disease. A myriad of assessments evaluate this important issue, both from the patient and clinician perspective.

**Quality of Life Assessments**

The **MS Quality of Life** is one of the best-known PRO instruments for the evaluation of health-related QOL in people with MS. This 54-item survey contains both generic and MS-specific questions relating to physical function, role limitations, pain, emotional well-being, energy, health perceptions, social function, cognitive function, health distress, overall QOL, and sexual function.

The **Short Form Health Survey** (SF-36) is a 36-item PRO intended to survey recent health status and quality of life (over the past 4 weeks). It assesses eight health concepts: limitations in physical activities because of health problems, limitations in social and everyday activities because of physical or emotional problems, pain, general mental health, energy and fatigue, and general health perceptions.

The **Canadian Occupational Performance Measure** is a PRO designed to capture an individual’s perception of their performance in everyday living, over time. Originally published in 1991, it is used in over 40 countries and has been translated into more than 35 languages.

The **Functional Assessment of MS** is a PRO consisting of 58 items. It investigates 6 primary aspects of QOL in people with MS: mobility, symptoms, emotional well-being, general contentment, thinking/fatigue, and family/social well-being.

The **Goal Attainment Scale** is a PRO focused on goal setting and achievement. Questions are customized to suit each person and scored individually based on their current and expected levels of performance. Each individual goal is rated on a 5-point scale and they are weighted with regards to relative importance to the individual. Individual scores for three to four goals are incorporated into a total score.
The **MS Impact Scale** is a 29-question PRO about the recent impact of MS on day-to-day life (over past two weeks). Twenty of the questions relate to the disease’s physical impact and nine relate to its psychological effects.

The **MS International Quality of Life Questionnaire** is an MS-specific PRO that is available in 14 languages. This questionnaire was developed from patient interviews and designed specifically to reflect patients’ perspectives of how MS affects their daily lives.

The **MS Quality of Life Inventory** (MSQLI) is a clinician-reported assessment that consists of 10 individual scales. It provides a QOL measure that is both generic and MS-specific and addresses many concerns that are relevant to the MS population. Scales cover topics such as health status, fatigue, pain, sexual satisfaction, bowel/bladder control, visual impairment, perceived deficits, mental health and social support.

MS disease severity is a helpful data point for clinicians in order to select and manage a course of treatment for someone living with the disease. They use a number of tools to gather this information.

### Disease Severity Assessments

The **Guy’s Neurological Disability Scale** is a PRO used to capture many aspects of disabilities that can be experienced by people with MS including cognition, mood, vision, speech, swallowing, fatigue, as well as limb, bladder, bowel and sexual function.

The **Patient Determined Disease Steps** is a patient-reported measure of disability in MS. Responses range from 0 (normal) to 6 (confined in a wheelchair).

The **Functional Independence Measure** is an 18-item clinician-reported scale that is used to assess and grade the functional status of a person based on the level of assistance he or she requires. Tasks that are evaluated include bowel and bladder control, transfers, locomotion, communication, social cognition as well as six self-care activities: feeding, grooming, bathing, upper/lower body dressing and toileting.
The **MS Functional Composite** (MSFC) is a standardized method of measuring the severity of MS that is primarily used in research. This 3-part assessment is based on scores from the T25-FW, 9-hole peg test and PASAT (described earlier).

MS rehabilitation therapy is often multi-faceted. It may include changing behavior patterns or making modifications to one’s environment. Physical or occupational therapists may recommend exercise or stretching, relaxation, strategies for keeping cool or conserving energy, or even something as simple as supportive foot ware. In some cases, assistive equipment or gait training may be advised. In order to implement or manage any of these interventions, rehabilitation experts must determine an individual’s health status. A wide variety of tests are used to do this. These instruments combine both the patient and clinician perspective, painting the most accurate picture of how a patient is doing. Armed with these tools, rehabilitation professionals can most effectively work with their clients’ toward living the best life possible with MS.

Opening Up New Possibilities

MS is a complex condition, which requires comprehensive, long-term management. While current disease-modifying therapies aim to reduce MS exacerbations and slow disease progression, none can cure the disease and repair the damage it does. Rehabilitation programs aim to improve the function, well-being and quality of life of individuals in the face of disease progression. In most cases they are the best option to preserve or improve the ability to participate in daily living activities for those whose conditions may be worsening. MS researchers are making significant progress toward
better understanding the underlying causes for disability and are improving rehabilitation techniques and programs.

The risk of falling is high in people with MS. To reduce this risk, clinicians frequently recommend a mobility aid, such as a wheelchair or a scooter, for those that are unsteady on their feet. A 2017 study evaluated fall risk in 44 participants with MS who use these devices as their primary means of mobility. Participants completed a survey that included questions about the frequency of falls, the circumstances surrounding them, and how they affected quality of life. Results show 75 percent of individuals with MS using a wheelchair or scooter report falling at least once every 6 months and 66 percent limited their activities because of concerns about falling. The majority of participants reported that their most recent fall occurred at home. The most common activity that was being performed when a subject fell was using the toilet. Other common activities included transfers to/from the wheelchair or scooter and reaching for objects. Data suggest many people with MS walk short distances in their home after being prescribed a wheelchair or scooter and often lose their balance at that time, but they still sustain falls while using these devices during everyday activities. Specifically, 67 percent of subjects using a power wheelchair or scooter reported they have fallen when using the device and almost 40 percent of manual wheelchair users reported the same. The research team concluded that clinicians must be aware the risk of falls continues to be high when a person with MS uses mobility devices and preventative interventions are needed. The research team is currently developing a comprehensive therapeutic program designed to educate people with MS who use wheelchairs about how to prevent and recover (get up) from falls. Such a program could be widely used to improve quality of life and reduce injuries for those living with the disease.

MS rehabilitation therapy can be administered on an inpatient or an outpatient basis. A 2016 study explored which of these two settings is best for MS rehabilitation. As part of this research, 146 subjects with MS were divided into three different groups: outpatient rehabilitation, inpatient rehabilitation and no treatment (subjects were placed on a waiting list for rehabilitation). Researchers concluded inpatient and outpatient rehabilitation approaches both significantly benefit subjects. Outpatient rehabilitation was more effective at improving subjects’ quality of life. However, investigators noted the inpatient
setting may be more suitable for those struggling with more severe disability, or for those preferring to be treated without the involvement of relatives or caregivers.

**Constraint-induced movement therapy** (CIMT) is a rehabilitation technique originally developed for stroke victims. CIMT works on the theory of “learned non-use,” which means when a limb is impaired people learn not to use it for daily activities. They therefore switch to using the better limb for everything. CIMT reverses this habit by placing a mitt over the functional hand and forcing individuals to use the impaired limb.

As discussed in our *April 2019 newsletter*, nerve networks in the brain change when an individual learns new things or memorizes new information. This ability to change is called neuroplasticity. These new nerve connections are reinforced and strengthened through behavior. With effective CIMT therapy, the brain “rewires itself” and movement of the affected arm or leg may be improved. Researchers at the University of Alabama at Birmingham (UAB) recently conducted a study in which 20 subjects with MS received either CIMT or complementary and alternative medicine (CAM) for upper limb weakness. The CAM group underwent 35 hours of holistic exercises such as pool exercise and yoga. The other group received the same amount of CIMT. Each subject’s functional ability was recorded before and after therapy. Results show CIMT to be significantly more effective than CAM at improving arm/hand function in MS. Specifically, subjects receiving CIMT improved on average 2.7 points on the scale ranging from 0 to 5 points, while those receiving CAM saw an improvement of only 0.5 points. Subjects were retested one year after therapy and found the same results, suggesting the benefit of CIMT is long-lasting. In a second study, the UAB study team used MRI to examine 20 subjects who underwent either CIMT or CAM. They found improved brain connectivity in CIMT subjects, compared to no changes in CAM subjects. This reinforces the concept that CIMT may help the brain rewire itself with resulting improved function. Investigators are planning further studies involving lower limbs, and to determine how long the benefits last. The end result of this research could introduce a new therapeutic technique to address weakness in MS.

Exercise is an essential component of rehabilitation therapy for MS. These exercise regimens may be tedious and repetitive and as a result, lack of motivation and boredom can affect a person’s adherence to the treatment. Exercise programs may also require
specialized equipment and supervision to ensure it is used correctly requiring those with MS in need of therapy to travel to treatment centers, which is not always convenient or even possible. Spanish researchers evaluated “virtual rehabilitation” as a means of exercising. As the name implies, this involves using virtual reality and natural user interfaces for physical activities. In this study, 11 subjects were randomly assigned to either exercise traditionally or by using a virtual reality system called RemoviEM. Subjects doing virtual exercise participated in 3 different activities: TouchBall (subjects touched virtual objects with their hands before they disappeared, while keeping their feet in place), TakeBall (subjects moved virtual objects from one position to another using both hands) and StepBall (subjects stepped on virtual objects before they disappeared, without touching them). Results showed subjects using RemoviEM experienced a greater improvement in balance and reach. In addition, virtual exercise was widely accepted, easy to use and safe. This suggests that virtual exercise represents a motivational and effective alternative to the traditional physical regimen. Of note, investigators are working to update and improve RemoviEM to include new rehabilitation exercises. Researchers in Italy also found technology-based exercise to be effective at improving balance in people with MS. They assigned 36 subjects randomly to perform traditional balance exercises, or an exercise regimen using the Nintendo Wii system. Subjects in the Wii group had significantly greater improvements in balance, suggesting that interactive visual-feedback exercises such as Wii may be an effective way of improving balance disorders in MS.

In MS the immune system damages nerves in the brain and spinal cord. The effects of this damage depend on what parts of the nervous system are affected. The cerebellum and brainstem process signals from various systems of the body including sensory, visual and the inner ear (vestibular system). Damage to these areas can cause problems with balance, which may be severe enough to cause falls. Researchers at the University of Colorado developed and are testing the effectiveness of a vestibular-related exercise program for people with MS called Balance and Eye-Movement Exercises for People with Multiple Sclerosis (BEEMS). This program includes three components: balancing on different surfaces; walking, both with and without head movements, and with eyes open.
and closed; and eye movement exercises. As part of this research, 88 participants with MS were randomly assigned to either complete the BEEMS regimen or be placed on a waiting list for the program. Results measured at six weeks showed that subjects in the BEEMS group experienced significantly greater improvements than the control group in balance, fatigue, cognition, dizziness and quality of life. These benefits were sustained at 14 weeks. Investigators are planning future studies to confirm these findings, determine how long the program must be for maximum benefit, and determine whether or not it needs to be supervised. BEEMS holds exciting potential in MS rehabilitation therapy, not only for its benefits, but also in the possibility that individuals may be able to participate in it remotely.

Researchers at the Shepherd Center are conducting the STEP for MS study (Supervised versus Telerehab Exercise Program for People with Multiple Sclerosis) to see if an at-home exercise program can help improve mobility and quality of life for people with MS. The team is comparing a home-based exercise program to one that takes place in a facility like a gym. A trained instructor teaches participants how to exercise and provides encouragement throughout the program, regardless of where they exercise. The iConquerMS portal is being used for data collection, and to communicate with participants. In addition, the team is looking at whether people have better mobility and quality of life when they get to choose where they exercise, compared with when the research team assigns them by chance to exercise at home or in a facility. The research team hopes to enroll 500 subjects across seven sites in the United States. Interested in joining the study? Contact information for each site, as well as criteria for participation, can be found on the STEP for MS website.

Many people with MS experience severe physical and mental fatigue. Investigators at the Kessler Foundation are studying whether a rehabilitation technique known as “feedback presentation” can relieve this troubling symptom. Feedback presentation is a technique that tells individuals how successful they are at performing a particular task. It has been shown to affect activity in areas of the brain thought to be compromised in individuals with fatigue (the fronto-striatal network). Positive feedback presentation (such as receiving food or money) increases brain activity and negative feedback presentation (not receiving a reward)
has the opposite effect. As part of this study, 14 healthy subjects and 19 subjects with MS performed a gambling task during functional magnetic resonance imaging (fMRI). Results showed all subjects receiving a monetary reward (positive feedback) experienced a significant decrease in fatigue. Scans showed significantly greater activation in different areas of the brain with positive and negative feedback. This is the first fMRI study showing that stimulation of the certain brain networks through positive feedback for attaining a goal (winning money) leads to decreased fatigue in MS subjects and healthy participants. This could help determine whether a feedback technique can reduce MS fatigue without medication, which would represent a major step forward for people with MS.

Functioning better and feeling productive adds enormously to the quality of life of people with MS and their families. Rehabilitation is more than an “extra” therapy that is given after other medical treatments. It is an integral part of managing and treating the diverse set of issues often encountered throughout the course of MS. As such, learning more about and improving therapeutic techniques is of vital importance to those living with the disease so they can live their best life every day. The core of ACP’s mission is to facilitate research efforts like these, that significantly impact the MS community.
Stubhy Pandav is the lead singer of the popular Chicago band, Lucky Boys Confusion. After having symptoms for many years, he was diagnosed with MS a year ago. The timing of his diagnosis was especially difficult as his wife was three months pregnant with their first child at the time. However, he has been undergoing MS treatment and his last MRI showed no active lesions. He feels very blessed that his disease is now stable and he is feeling good. Stubhy would like to raise awareness and funds so MS research can occur and hopefully one day a cure can be found.

The first annual concert “MS Sucks, Singing for a Cure” concert, hosted by Stubhy Pandav and benefitting ACP, will be held at 6PM on Saturday, December 21st, 2019 at The Bottom Lounge in Chicago, IL. The show will feature well-known bands such as Lucky Boy Confusion, The Plain White T's, and many others. The bands performing are donating their time and talent to support Stubhy, ACP, and to bring awareness to MS. Promotional merchandise will be available and there will be a raffle at the concert. Stubhy is directing proceeds to ACP to support our work to accelerate research in MS to improve the health, healthcare, and quality of life for those affected by MS.

If you’re interested purchasing tickets to the MS Sucks concert, please click here. Anyone interested in making a donation on Stubhy’s behalf can click here. For more information or questions, please contact Lindsey Santiago at lsantiago@acceleratedcure.org or 781-487-0013.
The MS Research Mythbusting Webinar is now Available Online!

While MS affects all races and ethnicities, minority populations may bear an unequal burden from the disease, including a higher risk of aggressive disease and disability. However, minority populations are severely underrepresented in scientific research. In fact, recent studies show that African Americans make up more than 13 percent of the U.S. population but only 5 percent of clinical trial participants and Hispanics, who make up 16 percent of the population account for only 1 percent of research participants.

To help raise awareness and address the misconceptions people often have about research participation in MS, the Multiple Sclerosis Association of America (MSAA) and ACP presented a national webinar, MS Research Mythbusting, on Tuesday, October 29, 2019. MS expert neurologist Mitzi Joi Williams, MD discussed the role research plays in improving the health and well-being of people affected by MS, and the reasons why participation from minority populations is needed to develop treatments for all affected by the disease.

Did you miss MS Research Mythbusting and would you like to see it? Were you able to attend and would you like to see the program again? The webinar is now archived on the MSAA website. Anyone interested in watching it can click here. This program is made possible through educational grants from Genentech and Biogen.
A Study to Understand Exercise Behavior in People with MS

Study Title: Social Cognitive Correlates of Physical Activity in Adults with Multiple Sclerosis in the United States.

Study Purpose:
Social cognition focuses on the role that thought processes play in our social interactions. Previous research suggests cognitive processes like social support, self-regulation and motivation significantly impact physical activity in adults in the general population. This study will evaluate various social cognitive factors that may be associated with exercise behavior in people with MS.

This study involves:
This study involves completing a questionnaire about your physical activity and health habits. The survey will take 25-40 minutes to finish. If you begin and want to finish later, you are able to save your progress and come back to answer the questions for up to one week. The valuable feedback that you provide will be used to help inform future exercise interventions for people with MS.

Participating locations:
The University of Alabama at Birmingham

Researcher:
Robert Motl, Ph.D.
Recruiting:
Anyone that is 18 years of age or older and has been diagnosed with MS is welcome to participate in this study. We hope that 1000 people across the United States will complete these questionnaires. Participation in this study is completely voluntary.

Study website:
If you are interested in participating in this study, please click here, or e-mail Stephanie Silveira at enrl@uabmc.edu.

Real MS™ (Research Engagement About Life with MS)

In the summer of 2016, the iConquerMS initiative launched REAL MS, a longitudinal study of MS. REAL MS participants complete questionnaires online twice each year on a variety of subjects, including health history, diet, exercise and their experience with MS. A seventh round of REAL MS surveys are now available through the iConquerMS portal. Completing these surveys is one of the simplest ways you can accelerate MS research. The information collected will play a pivotal role in helping scientists and clinicians gain a better understanding of the health and quality of life over time for people with MS. REAL MS is just one of the many ways iConquerMS is facilitating research on topics of importance to people affected by the disease. If you are not already a member, please consider joining iConquerMS, the only people-powered research network for MS. Already a member? Please log in to your account and complete your open surveys!
NEW RESEARCH RESULTS

A new MS Treatment is approved!

On October 30, 2019, Biogen announced that the U.S. Food and Drug Administration (FDA) approved Vumerity™ (diroximel fumarate), a novel oral therapy for the treatment of relapsing forms of MS. Diroximel fumarate is in the same class as Tecfidera® (dimethyl fumarate), but is believed to cause fewer gastrointestinal side effects, such as diarrhea, nausea, vomiting, and abdominal pain, than Tecfidera. This marks the culmination of a multi-year development program in partnership with Alkermes (a biopharmaceutical company in Ireland) and with the help of nearly 1,100 subjects participating in the research. With the approval, Biogen intends to make Vumerity available in the United States in the near future.

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