More than 2.3 million people worldwide currently live with MS, with more than 1 million of those living with progressive MS. Generally speaking, there are two progressive forms of the disease. Secondary progressive MS (SPMS) occurs as a second phase of the disease for most individuals with relapsing remitting MS (RRMS). In these cases, relapses and periods of remission change into symptoms that steadily get worse. This shift typically begins 15 to 20 years after an individual is first diagnosed. Approximately 10 to 15 percent of people with MS have primary progressive MS (PPMS), where neurologic functions steadily worsen from the beginning. There are no flares in disease activity and there is no recovery, or remission. Our first article contains information aimed at better understanding progressive MS, including its symptoms, how it is diagnosed, as well as recent findings in progressive MS research.

Significant progress has been made in the treatment of RRMS over the past 25 years, with more than a dozen disease-modifying therapies available for this form of the disease. Treatment of progressive MS has been a major focus in MS research, but has remained a mystery until recently. New milestones have been reached in the past year, with a first-ever treatment for PPMS now available, and new treatment options for SPMS. Efforts to better understand and treat progressive MS continue with more novel treatments in the pipeline. Learn more about both the approved and emerging treatments for progressive MS.
People living with progressive MS experience a worsening of symptoms over time that gradually results in functional loss and increasing disability. To say that living with progressive forms of the disease is difficult would be a huge understatement. Progressive MS is relentless, unfair, painful and debilitating. It never takes a day off or offers much in the way of relief. For many, living with progressive MS involves constantly managing MS symptoms and treatments, prioritizing what needs to be done in a day, and learning how to best deal with the uncertainty of the future. While there is no approved treatment that can reverse the damage progressive MS causes, there are ways to overcome the challenges it poses. Our third article offers helpful information and tips on how to live the best life possible with progressive MS.

Our Research Spotlight contains opportunities to participate in research, MS events, as well as new innovations in MS research. This month we feature REAL MS, a longitudinal study of MS, which is open to everyone living with MS (including caregivers). Also featured is a Multiple Sclerosis Summit hosted by the MS Coalition. In addition, researchers at Octave Bioscience recently revealed exciting new results from one of their studies on biomarkers of MS disease activity. Click here to learn more!

We hope you enjoy this newsletter and encourage you to share it with anyone you think may be interested in learning more about MS research.

Jan and Lindsey, on behalf of the Accelerated Cure Project Team
Understanding Progressive MS

More than 2.3 million people worldwide currently live with MS, with more than 1 million of those living with progressive MS. Generally speaking, there are two progressive forms of the disease – secondary progressive MS (SPMS) and primary progressive MS (PPMS). SPMS is common, occurring as a second phase of the disease for most individuals with relapsing remitting MS (RRMS). In these cases, relapses and periods of remission change into symptoms that steadily get worse. This shift typically begins 15 to 20 years after an individual is first diagnosed.

Relapses can still occur in people with SPMS, however they tend to be less well defined and recovery is not as complete. SPMS can be classified further as being active or non-active, with or without progression, or stable. An individual with active SPMS experiences relapses or evidence of new disease activity on MRI. Non-active SPMS means there is no evidence of current disease activity. In a case of SPMS with progression, a person experiences worsening symptoms over time. SPMS without progression means there is no evidence of the condition getting worse. Stable SPMS is when neither disease activity nor progression is seen.

Once MS advances to the secondary-progressive stage, symptoms often become more challenging. These symptoms may include common symptoms of RRMS, such as numbness or tingling, bladder control problems, changes in vision, walking difficulties, and excessive fatigue. Other symptoms that may indicate a transition to SPMS include increased weakness and more difficulty with coordination, stiff or tight leg muscles, and increased depression or problems thinking. As with all types of MS, symptoms vary widely from one person to another and not everyone will have all of them. Which symptoms are experienced depends on where lesions are located in the brain and spinal cord. Most people with SPMS experience their symptoms regularly, with more or less intensity (depending on if they are having a relapse).
Secondary progressive MS can be hard to diagnose because the transition happens gradually. At least six months of progression must be observed before RRMS can be considered secondary progressive. Therefore, it’s important for people with MS to keep track of their symptoms and communicate any changes to their healthcare team. A careful history of these changes, repeat brain MRI scans and a neurologic examination can help determine if the disease has actually progressed to SPMS.

MS researchers are working to better understand the secondary progressive phase of MS. Studies show men tend to progress to SPMS faster than women. Researchers in South Africa suggest that consumption of saturated fats (found in such foods as red meat and full-fat dairy products) not only increases the risk of developing MS, but is also linked to disease progression. The brain is divided into two types of tissue – white matter and gray matter. White matter is found in the deeper tissues of the brain (subcortical), and gray matter is found on the surface of the brain (cortical). Investigators in Japan suggest injury to the gray matter of the brain (specifically the cerebral cortex) plays a major role in the accumulation of long-term disability in people with MS. Results show lesions or atrophy in this area of the brain may play a significant role in the transition to SPMS. A 2018 study also found subjects with a larger number of cortical (surface) lesions at disease onset had a higher risk of developing SPMS and the transition occurred sooner. Specifically, data showed subjects with two cortical lesions had more than double the risk of developing SPMS, those with five cortical lesions were almost 5 times more likely to develop SPMS, and those with seven or more cortical lesions had a more than 12-fold higher risk of developing SPMS. In addition, data showed other factors, such as older age at disease onset and three or more relapses early in the course of the disease also predicted a higher probability of developing SPMS.

Studies suggest long-term treatment with disease modifying therapy (DMT) may influence the likelihood or timing of the transition to SPMS. Swedish investigators studied a cohort of RRMS subjects from the Swedish National MS Registry. Their findings suggest subjects on DMT for an extended period of time (12 years) took longer to transition to SPMS.
recent Spanish study demonstrated long-term treatment with DMT (13 years) lowers the likelihood of RRMS progressing to SPMS, as well. Interestingly, their results showed DMT does not appear to benefit those subjects that have already progressed to SPMS. Data suggest factors that may also increase the risk of disease progression in subjects with RRMS include multifocal relapses (experiencing more than one symptom during a relapse), being older than age 34 at disease onset (older subjects had a four times greater risk of progressing to SPMS), and failure to respond to one’s first disease-modifying therapy.

Approximately 10 to 15 percent of people with MS have PPMS, where neurologic functions steadily worsen from the beginning. There are no flares in disease activity and there is no recovery, or remission. How fast the disease progresses may vary. This type of MS affects men and women equally and the average age of onset is approximately 10 years later than in relapsing forms of the disease. On average, people with PPMS start having symptoms between ages 35 and 39. In general, people with PPMS tend to require more assistance with their everyday activities and have more difficulty remaining in the workforce.

Some people with PPMS experience temporary plateaus and sometimes minor, temporary reductions in symptoms. This form of the disease can be further characterized at different points in time as either active (MRI shows more lesions and disease activity) or not active (symptoms continue, but the disease is not causing further lesions), and with progression (levels of disability are increasing and symptoms are getting worse) or without progression (the disease is not causing further disability and symptoms are steady).

PPMS symptoms vary from person to person, both in type and severity. Because PPMS primarily affects the nerves in the spinal cord, the main symptoms often involve difficulty walking, weak or stiff legs and problems with balance. Other common symptoms include speech or swallowing issues, vision problems, fatigue, pain, Lhermitte sign (an electric shock sensation that runs down the back and limbs when the neck is bent), paralysis, numbness or tingling, dizziness, shakiness,
trouble thinking clearly, mood changes or depression, sexual problems, as well as bladder and bowel dysfunction.

Symptoms commonly associated with PPMS may occur in all forms of MS. In order to determine a diagnosis of PPMS, a person must experience symptoms that consistently worsen over the course of 1 year. Given that diagnosis is based on an individual’s symptom history, accurate tracking of MS symptoms is essential. In addition to having progressive symptoms, a person must exhibit at least two of the following criteria: (1) brain lesions on MRI that are typical of MS, (2) two or more MS lesions in the spinal cord, or (3) evidence of oligoclonal bands or an elevated IgG index in the spinal fluid, both of which are indicative of immune system activity in the central nervous system. Repeated diagnostic testing is necessary in order to obtain this information. It’s important to keep in mind it may take time for a PPMS diagnosis to be made, particularly if a person has only recently begun to experience neurological symptoms.

A distinct type of damage to the brain and spinal cord occurs in PPMS. It involves much less inflammation, which is typical in relapsing forms of the disease. As a result, people with PPMS tend to have fewer brain lesions and the lesions tend to contain fewer inflammatory cells. As mentioned earlier, individuals with PPMS tend to have more lesions in the spinal cord. In 2014, Canadian researchers conducted a literature review to identify risk factors that may be associated with PPMS. They performed a search of six databases and included twenty observational studies in their review. They found very few studies have reported findings by disease course (the majority focus on RRMS). For example, exposure to Epstein-Barr virus appeared to increase the risk of RRMS, but its association with PPMS was less clear. Other risk factors, such as cigarette smoking and other infections were not consistently associated with a specific disease course. This review exposes a need for further study to better understand the risk factors associated with the onset of PPMS.

The International Progressive MS Alliance (the Alliance) is a growing global initiative to end progressive MS. The Alliance, founded by a number of international MS organizations, awarded more than $2.7 million dollars in research grants in the last year to support promising MS research around the world. These studies are aimed at understanding progression, accelerating clinical trials, and improving the wellbeing of
people living with progressive MS. A Scientific Steering Committee (a team of researchers, health professionals and people affected by progressive MS) provides expert perspective and strategic direction for the Alliance. This level of international participation and collaboration is unprecedented and holds great promise for groundbreaking discoveries toward better understanding, treating and, ultimately, ending progressive MS.

Progressive MS – Emerging New Treatment Frontiers

Significant progress has been made in the treatment of relapsing remitting MS (RRMS) over the past 25 years, with more than a dozen disease modifying therapies (DMTs) available for this form of the disease. Treatment of progressive MS has been a major focus in MS research but has remained a mystery until recently. New milestones have been reached in the past year, with a first-ever treatment for primary progressive MS (PPMS) now available, and new treatment options for secondary progressive MS (SPMS). Efforts to better understand and treat progressive MS continue with more novel treatments in the pipeline.

The DMTs used to treat RRMS typically work by decreasing inflammation and reducing the number of relapses an individual may have. These drugs are not usually effective in treating PPMS because this form of the disease does not involve significant inflammation. They may be effective in people with SPMS who still experience relapses however there is evidence that DMTs don’t work for those whose symptoms just get gradually worse.
New treatments for progressive MS

In March 2017, the U.S. Food and Drug Administration (FDA) approved Ocrevus (ocrelizumab) as the first and only treatment for PPMS. This approval was based on results of the ORATORIO trial, in which 732 subjects with PPMS received either ocrelizumab or placebo. Results showed ocrelizumab treatment slowed disability progression, reduced brain lesion volume and brain atrophy, compared to treatment with placebo. Ocrevus is a first-line treatment, which means that there are no recommendations for people to try other MS therapies before taking it. It is taken by infusion every 6 months. Ocrevus reduces nerve degeneration by lowering the number of a certain type of white blood cell (lymphocytes) in the blood that cause the immune system to attack the protective coating that surrounds nerves (the myelin sheath). While the approval of this medication opens up new possibilities for adults with PPMS, it’s important to note that Ocrevus has not yet been tested in children.

There are two new treatment options for those living with SPMS. Mavenclad (cladribine) was approved for RRMS and active SPMS in March 2019. Research shows it decreases the number of MS relapses, slows the progression of physical disability, and reduces disease activity as seen on MRI. Cladribine is an oral treatment, taken in two treatment courses, twelve months apart. It targets lymphocytes without suppressing the immune system continuously. It’s important to note that Mavenclad, like many DMTs, has significant risks. Serious side effects include an increased risk of cancer, fetal harm, decrease in white blood cells, as well as an increased risk of infections and liver injury. As a result, it is generally recommended in people with MS who have had an inadequate response to, or are unable to tolerate, another MS therapy.

Mayzent (siponimod) also gained FDA approval in March 2019 as a first-line treatment for adults with RRMS (including clinically isolated syndrome) and active SPMS. Siponimod acts by retaining lymphocytes in the body’s lymph nodes, keeping them out of circulation and out of the central nervous system (the brain and spinal cord). The effectiveness of this oral treatment was demonstrated in the EXPAND study (the largest phase III clinical trial in SPMS), involving 1,651 participants with SPMS. Subjects taking Mayzent had significantly less progression of disability and fewer relapses than those taking placebo. Of note, this benefit was not seen in study participants with non-active SPMS.
Chemotherapeutic agents are used to stop the multiplication of rapidly growing cells, either by killing the cells or by stopping them from dividing. These drugs are typically used in the context of cancer, however they are also used to treat autoimmune conditions, such as rheumatoid arthritis and MS. In MS, chemotherapy works by killing or inhibiting lymphocytes (which drive the immune system attack).

**Chemotherapy treatments for progressive MS**

**Novantrone** (mitoxantrone) is used for worsening RRMS and SPMS. It is administered intravenously by an infusion once every three months. There is evidence to suggest mitoxantrone reduces the number of MS relapses and disability progression. However, it has serious side effects, including heart problems and leukemia. As a result, individuals taking it require regular cardiac monitoring and there’s a limit to how much one can take. Specifically, an individual can receive a total maximum dose of no more than 140 mg over the course of their lifetime (which covers about 2 years of MS treatment). It’s usually used to treat people with disease that gets worse quickly when other treatments don't work.

**Methotrexate** is often used to treat rheumatoid arthritis. It has also been proven effective in the treatment of people with SPMS. Two clinical trials, a 2001 study and a 2004 study, show it reduces disability in subjects with progressive MS. Methotrexate has fewer side effects and is less expensive than other treatments. It may be considered as a therapeutic option in people with comorbid rheumatological disorders, those who have financial constraints, or individuals not willing to take a more aggressive treatment.

**Antibodies** are protective proteins produced by the immune system in response to the presence of a foreign substance, called an antigen. **Monoclonal antibodies** are pure antibodies, which are made in the lab to mimic the body’s immune system. Scientists can design antibodies that specifically target a certain antigen, and then make copies of that antibody in the lab. They are used to treat many diseases, including rheumatoid arthritis and cancer. Researchers are studying their effectiveness in treating progressive MS.
Monoclonal antibody treatments for progressive MS

The ASCEND trial looked at the ability of Tysabri (natalizumab) in slowing disease progression in subjects with SPMS. While subjects in this study showed improvement in upper limb disability as compared to lower limb, researchers concluded it did not reduce disease progression. Longer-term trials are needed to assess its benefit in SPMS.

Rituximab was tested in two trials, one of which was terminated early and the other trial failed to show any effect in this regard. However, the recent approval of ocrelizumab in PPMS suggests that Rituximab (an antibody with a similar mechanism of action) may be useful and warrant further research.

A recent study of 15 subjects with SPMS showed treatment with Lemtrada (alemtuzumab) resulted in improvement in disability and cognition. This suggests that alemtuzumab may provide a treatment option for SPMS patients. Additional larger scale studies are needed to confirm these results.

Researchers are evaluating a number of other agents for the treatment of progressive MS, with promising results that warrant further study.

New treatment possibilities for progressive MS

Statins are a group of drugs that act to reduce levels of fats, including triglycerides and cholesterol, in the blood. There is evidence they may be a promising treatment for progressive MS. The Multiple Sclerosis - Simvastatin Trial (MS-STAT) investigated treatment with high-dose Zocor (simvastatin) versus placebo in 140 subjects with SPMS. Results showed simvastatin reduced the rate of whole-brain atrophy compared with placebo and was well tolerated and safe.

Tyrosine kinases play a role in many cell functions, including cell signaling, growth and division. They are a type of targeted therapy, often used to treat cancer. In a small clinical trial of 35 subjects with PPMS and relapse-free SPMS, subjects were given masatinib (an oral tyrosine kinase inhibitor) or placebo. Subjects taking masatinib had
improved Multiple Sclerosis Functional Composite (MSFC) scores (suggesting less impairment), compared to worsening scores in subjects on placebo and treatment was well tolerated. This improvement was seen as early as 3 months into therapy and was sustained at 18 months. These data suggest that masitinib may have therapeutic benefit for those with PPMS and relapse-free SPMS and could therefore represent an innovative avenue of treatment for progressive forms of the disease.

Ibudilast is an anti-inflammatory drug that has been used in Japan to treat asthma for almost twenty years. More recently, it has been found to have anti-inflammatory activity in the central nervous system, which is of potential use in the treatment of MS. A phase II clinical trial, known as SPRINT-MS, recently investigated treatment with ibudilast in subjects with progressive MS. The trial was conducted at the Cleveland Clinic and 27 other sites across the U.S. and enrolled 255 people with PPMS or SPMS. The results suggest that Ibudilast is well tolerated and significantly slows the rate of brain atrophy compared to placebo.

Results from initial studies are encouraging enough for two new agents to advance to larger MS clinical trials.

Emerging progressive MS treatments

Researchers in France found that treatment with high-dose biotin (a water-soluble B vitamin) resulted in sustained reversal of disability in subjects with progressive MS, and treatment was well tolerated. As part of this study, 154 subjects with worsening disease in the previous 2 years received high-dose biotin (100 mg) or placebo for 12 months. Biotin treatment reduced EDSS scores by more than 1 point and decreased the time for subjects to walk a distance of 25 feet by more than 20 percent (both indicators of improvement in MS-related disability). This benefit was sustained for the duration of the study. A larger clinical trial is underway to confirm these results.

Lipoic acid is a naturally occurring antioxidant in the body. A 2017 study looked at lipoic acid treatment compared to placebo in 51 subjects with SPMS. Subjects taking lipoic acid
had significantly less brain atrophy over a 2-year period (which suggests a sustained clinical benefit in SPMS) and it was well tolerated. A multi-site clinical trial is currently enrolling subjects to further document these findings.

As discussed in our July 2018 newsletter, stem cell therapy is a restorative therapy that has shown substantial benefit in patients with RRMS. A number of studies suggest this type of therapy may hold promise for those with progressive forms of the disease. A small Phase II study in which 10 subjects with SPMS received IV administration of mesenchymal stem cells (MSCs) showed subjects experienced better visual acuity and improved evoked potentials as a result of treatment. A pilot study conducted at the Tisch MS Research Center of New York found intrathecal administration of MSCs (injection into the spinal cord) resulted in clinical improvement in 4 out of 6 subjects with progressive MS. Researchers in the United Kingdom are conducting the ACTiMUS trial to compare the effectiveness of autologous hematopoietic stem cell transplant (HSCT) in PPMS and SPMS. They recently completed a phase I trial of this treatment in progressive MS with favorable results and hope the ACTiMUS trial will confirm these findings.

A wide variety of medications are used to treat specific symptoms of progressive MS. These include, but are not limited to, bladder and bowel problems, erectile dysfunction, fatigue, pain, and spasticity. Maintaining healthy lifestyle habits can also make a difference. For example, people with progressive MS may be able to relieve some symptoms with exercise and stretching. This can preserve mobility, control weight gain, and increase energy levels. Eating a nutritious diet and staying on a regular sleep schedule may also be beneficial. Some people find that massage, meditation, or acupuncture help to relieve stress and ease pain. Physical and occupational therapy can also teach strategies for increasing mobility and managing symptoms. As discussed in our June 2019 newsletter, assistive devices can help people with progressive MS function and help maintain their independence. Accessibility accommodations and services, such as special parking permits, may also be helpful in this regard.

People living with progressive MS face the possibility of gradually losing function with each passing day, potentially losing the ability to do the things they enjoy. Accelerating
research efforts focused on finding effective treatments for progressive MS is of prime importance. With new knowledge gained from current and future studies, there’s hope the quality of life for those living with progressive forms of the disease can be improved and the uncertainty they face can be minimized. ACP is dedicated to facilitating research into topics like this that impact the MS community.

Overcoming the Challenges of Progressive MS

MS is a variable, unpredictable disease. Its symptoms differ from person to person and from time to time in the same person. Those living with progressive MS experience a worsening of symptoms over time that gradually results in functional loss and increasing disability. To say that living with progressive forms of the disease is difficult would be a huge understatement. Progressive MS is relentless, unfair, painful and debilitating. It never takes a day off or offers much in the way of relief. For many, living with progressive MS involves constantly managing MS symptoms and treatments, prioritizing what needs to be done in a day and learning how to best deal with the uncertainty of the future. While there is no approved treatment that can reverse the damage progressive MS causes, there are ways to overcome the challenges it poses.

As discussed in our June 2019 newsletter, approximately two thirds of people with MS have difficulty walking. Gait difficulties tend to worsen as the disease progresses. Assistive technology offers a wide variety of tools and devices that allow individuals struggling with disability to stay active and ambulatory. Modifications such as ramps and
grab bars may be necessary to improve accessibility and safety at home. Rehabilitation professionals can help recommend appropriate devices and home modifications to optimize one’s independence. AbleData is an online database of information on thousands of assistive technology products that can be researched by type or topic. The Multiple Sclerosis Association of America’s (MSAA’s) Equipment Distribution program offers a wide variety of these products free of charge to individuals with MS who qualify for assistance. Something as simple as rearranging one’s home can make life easier, for example, putting frequently used things within easy reach. The National MS Society’s (the Society’s) brochure entitled “At Home With MS” offers many ideas on adapting one’s environment to the changes that progressive MS may bring.

A high percentage of people with MS are sensitive to heat and experience a worsening of symptoms, or new symptoms, when their body temperature rises. For this reason, many avoid hot showers or baths, or use fans and air-conditioning to stay cool in hot weather. Some people with MS tend to get overheated when they exercise. If this is the case, doing outdoor activities during the cooler hours of the day, exercising in an air-conditioned gym, or swimming may be helpful. Other helpful strategies include staying hydrated, wearing a cooling vest or neck wrap, taking cool down breaks, and staying out of direct sunlight. MSAA’s Cooling Distribution program offers cooling vests and other accessories to help cool the neck, wrists and ankles. MSAA provides these products at no charge and items are shipped directly to the client. Some people with MS experience an increase in symptoms in cold weather, too. Therefore, it’s also important to try to stay warm when temperatures are frigid. It may be helpful for people with progressive MS to keep a journal to track what makes their symptoms worse (the idea being once triggers are determined, they can be avoided).

As mentioned in our March 2019 newsletter, sleep is essential to functioning well, mentally and physically. It’s essential for people with progressive MS to practice good sleep hygiene. This can be done by sticking to a consistent sleep schedule, keeping the bedroom dark, quiet, and cool, avoiding too many fluids before bedtime and creating a relaxing bedtime routine. It’s also important to address any specific issues that are interrupting sleep or making it hard to fall asleep. Anxiety, muscle spasticity, frequent
nighttime urination, restless legs syndrome, sleep apnea, and depression are common in people with MS and can disrupt sleep.

Studies show depression is common in people with MS, affecting approximately half of those living with the disease. Many aspects of living with MS, and the disease itself, have the potential to cause depression. It can occur in any person with MS at any point in the course of the disease. Feelings of despondency are a normal reaction to the changes and losses that can accompany progressive MS. When depression occurs, it requires the same careful assessment and treatment as any other symptom of MS. Left untreated, it has the potential to reduce quality of life, make other MS symptoms, such as fatigue, pain, or cognitive changes, feel worse, and may be life threatening. Fortunately, depression is one of the most treatable of all MS symptoms. Studies show the most successful treatment plan is to seek counseling in conjunction with a prescribed drug therapy. Healthy living strategies (a healthy diet, regular exercise, reducing stress, etc.) can be very helpful in many regards, including coping with these feelings.

Eighty percent of people with MS experience fatigue, and over half rank it as one of their most troubling symptoms. Living with progressive MS drains energy levels very quickly. Fatigue is complex with many contributing factors (including depression and difficulty sleeping). As a result, its management also has many dimensions. In some cases drugs may be used to treat fatigue but, medication is generally not a solution to fatigue on its own. Because different factors can cause or add to MS-related fatigue, anti-fatigue medications should be used in conjunction with treatment for factors like depression and sleep issues (when applicable). It’s also important for those struggling with fatigue to see their physician regularly to ensure their MS is under the best control possible. Other useful strategies include reserving one’s energy for necessary activities and thinking ahead when commitments may be overwhelming. Leaving the house can require careful planning for those with advanced MS. Such factors as accessibility and parking are factors that must be considered and planning ahead is a must.
As alluded to earlier, living a healthy lifestyle is paramount for people with progressive MS (and in general). For example, eating wholesome food can help a person have more energy and also prevent other chronic health conditions, such as heart disease. Exercise is important for everyone with MS, both for fitness and for function. Regular exercise promotes flexibility, can improve balance, and may also help with common MS complications, such as constipation, trouble sleeping, and cognitive issues. Those with advancing disability may benefit from working with a physical therapist to identify exercises that will strengthen muscles that are weak and help reach specific goals, such as walking more easily or improving foot drop. It may be necessary to modify favorite activities or find new ones to enjoy. In either case, it’s important to stay active. Smoking is a big risk factor for developing MS as well as for the worsening of the disease. According to the National MS Society, this includes exposure to secondhand smoke. While smoking is unhealthy for everyone, it’s a particularly harmful lifestyle choice for people with progressive MS. Research suggests stress may also trigger MS symptoms or make them worse. Having any chronic illness is likely to increase stress levels and MS is no exception. Reducing stress through meditation, or other stress-reduction practices (yoga, exercise, connecting with others or just maintaining a sense of humor, to name a few) may help improve quality of life, as well as possibly slow disease progression.

It’s important for people with progressive MS to maintain their physical health. As discussed in our July 2019 newsletter, people with MS have been found to have more co-existing health conditions than the general population. These other illnesses, called comorbidities, not only compromise one’s overall health, they are also associated with more rapid MS progression. Therefore, preventing or effectively treating comorbidities is essential to improving MS outcomes. It’s important to maintain an ongoing relationship with a primary care provider to ensure appropriate preventive health measures are followed (such as flu shots and recommended health screenings) and any comorbidity is adequately identified and treated. The complexity of MS and the multitude of comorbid conditions that individuals with MS may experience require coordinated, comprehensive care with many clinicians taking a team approach. It is essential for people with all forms of MS to be engaged with a diverse team of healthcare providers with the
expertise to manage their MS and any other health conditions they may have.

Maintaining one’s mental health is key to overcoming the challenges posed by progressive MS. Spiritual beliefs can play a significant role in this regard. Many rely on prayer to get through difficult times. Religious advisers may offer important advice and support. As discussed earlier, treating depression is very important. Some find solace in simply accepting their “new normal” and choosing to move forward every day. Increasing disability often means not being able to participate in activities once enjoyed. Maintaining a good attitude and staying thankful for remaining abilities may help adjust to these changes. If possible, viewing limitations as hurdles to go over rather than insurmountable walls may help brighten one’s outlook. If it’s not possible to make it over a certain “hurdle”, figuring ways around it instead of giving up may be a way to boost morale.

Keeping busy can be a good way to maintain a sense of normalcy. For those who can’t work, volunteering, starting a new hobby, or adopting a pet are good ways to fill idle time. Going on vacation can go a long way toward improving mental health. It may take extra planning, but vacations can be as much fun as ever. Just remember to slow down, keep limitations in mind (don’t try to visit 5 cities in one week) and be flexible. As discussed in our June 2019 newsletter, it’s important for people with MS to keep their brain engaged and stimulated. Mentally challenging activities, such as crossword puzzles, word games, memory games, taking classes or reading, all help to keep one’s mind sharp. Staying socially active also helps mental function and staves off loneliness at the same time.

The challenges of progressive MS can be very isolating, however it’s important not to face them alone. A good support system is needed. Connecting with others who are affected by the same challenges can help one learn new information and discover different strategies for coping or dealing with problems. This fellowship allows one to both give and receive support (both of which are very therapeutic). The Society offers a number of resources to help fend off isolation and help people with progressive MS find the support they need. The MS Navigator program can provide information to individuals living with the disease, help one find a support group or healthcare provider, provide wellness strategies or even crisis intervention in times of need. MSconnection.org is a social networking website and community that enables those living with MS to interact in a safe and secure environment.
Community members can connect based on things they may have in common, such as symptoms, treatment, where they live, or mutual interests. The Society’s Peer Connections program offers someone who has “been there” to provide tips, suggestions and emotional support to help one navigate the trials MS may impose. The MSFriends program offers the opportunity to connect with volunteers living with disease. They know first-hand what it is like to live with MS and can help deal with any changes brought about by the disease. The Society also offers a number of local support groups that bring together people with similar experiences to learn from and support each other. The Edward M. Dowd Personal Advocate Program offers case management services in situations where needs are complex and support systems are lacking.

Overall, it’s important for people living with advanced MS to find ways to make each day a little easier. Some adopt a different strategy of doing things, such as pacing activities, or using a tool that makes a specific task easier (for example, a jar opener). Online shopping saves time and energy to purchase essentials and other items one may wish to buy. For those that can, hiring a housekeeper to help with cleaning and laundry makes a big difference. For those that are employed, working from home, whenever possible, is a wonderful way to simplify life. In all cases, taking breaks when one starts to feel fatigued is essential.

MS isn’t a disease that can be completely controlled and living with it is a process. Despite the best management strategies, interventions and treatments, the disease may take its own course and disability may occur. Some days may feel manageable, while other days may not. For some people, having MS puts their priorities into perspective; for others, it may feel more like an obstacle in the way of all their plans and dreams. For anyone, feelings of sadness, loss, anger or anxiety are common and may occur at any time over the course of the disease. It’s important for those living with persistent symptoms and advancing disability to arm themselves for the hard days, but also to celebrate the good days. Staying resilient may be a challenge, but there are ways to make this easier. Reach out to resources that are available for people with MS. Find meaningful ways to be productive and fulfilled. This may involve developing new mental, emotional and
spiritual “muscles.” Keep in mind these goals may take time. But remember people with progressive MS can, and do, pass through dire periods. Some find resilience in their faith, support groups or by tapping their sense of humor. Others do so with the help and support of family and friends. Keep in mind many things can be done to maintain good health, treat MS symptoms, improve quality of life and maximize the ability to function.

October 2019 Research Spotlight

EVENTS
RESEARCH OPPORTUNITIES

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 innovations in MS Research – Biomarkers of MS disease activity

Researchers at Octave Bioscience presented results from one of their recent studies at the 2019 European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) conference in Stockholm, Sweden. The purpose of this study was to investigate the performance of multivariate protein biomarkers (those involving two or more proteins) to classify disease activity in subjects using serum samples obtained from the ACP Repository. Results showed multivariate biomarkers representing several pathways involved in the MS disease process effectively classified subjects experiencing an exacerbation versus those without disease activity better than any single biomarker. More research is needed to verify these results and to further investigate these biomarkers in different demographic groups. The study team is investigating various outcomes relating to disease activity, such as inflammation, immune response and neurodegeneration, to guide the development of a biomarker assay with the goal of monitoring MS disease activity status in the clinic. This study is just one of more than one hundred studies using ACP Repository samples to advance and accelerate research into MS.