Over the years, advances in technology have revolutionized many aspects of daily life for a majority of people. With 3D technology, architects and designers now produce their models and presentations with more details. Since the inception of the Internet, it’s become common for individuals to communicate, shop, pay bills or meet their significant other online. Big data plays an important role in many industries, including business, finance, sports and medicine. Technological innovations are bringing better treatment for individuals with health conditions that were previously difficult to diagnose. They are also opening up new possibilities for people living with MS. Our first article sheds light on the vast array of mobility assistive technology to help those with ambulatory difficulties, including some new and upcoming devices.

Studies suggest that up to 65% of people with MS have problems with aspects of thinking, such as memory, concentration, organization or problem solving, at some point in the course of their disease. These difficulties can develop insidiously and have a big impact on daily life. Assistive technology for cognition helps with these cognitive processes. Research suggests brain-training programs can improve brain functioning in people with MS. There is also evidence that those who maintain mental activity, such as reading or puzzles, are able to withstand considerable disease burden (white matter lesions or brain atrophy) without cognitive impairment. Learn more about some fun ways to stimulate the brain and how this may slow cognitive decline in MS.

The World Health Organization (WHO) refers to telemedicine as “healing from a distance.” It is the remote delivery of healthcare services using telecommunications technology. Telemedicine allows healthcare providers to evaluate, diagnose and treat patients remotely, without the need for an in-person visit. It can be used for a wide variety of health services, including MS care. Many patients consider it an energy, time and cost saving way to see and speak to a clinician for minor and non-urgent medical needs instead of going to a doctor’s office or emergency department. Healthcare providers see it as an efficient way to provide care to those who may live in rural areas, or have difficulty making it to an appointment. Despite these many benefits, there is much controversy surrounding the practice of telemedicine. Read more about this growing trend in the healthcare industry.
Genomics may play a key role in understanding how to effectively treat autoimmune diseases like MS. Our Repository Spotlight focuses on DxTerity, a genomics company. DxTerity is developing a low-cost, user-friendly, mailable device for RNA monitoring at home. This information may help people with MS and their physicians conveniently monitor disease activity, and may allow for more effective treatment choices based on an individual’s biology.

Our iConquerMS Spotlight highlights research iConquerMS is conducting in partnership with the National MS Society and Dr. Mitch Wallin. We will soon be releasing a survey to the iConquerMS community on awareness, utilization, and experiences with telehealth. Your data will help us better understand the types of people who use or would like to use this new technology and may one day help revolutionize MS care!

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

Keep Moving With MS

According to the National MS Society, approximately two thirds of people living with MS have some level of difficulty walking. Many MS symptoms can interfere with mobility, such as fatigue, pain, numbness, weakness, spasticity, lack of coordination, and vision problems. Even depression, which is very common in MS, can interfere with a person’s ability to stay mobile and active. Difficulty getting around has the potential to interfere with many aspects of daily life, social events, work, as well as the ability to travel. A few basic strategies may help individuals with MS maintain locomotion. Ongoing management of MS symptoms, either with medications or other therapies, is essential. Adjustments to the home and/or workplace can also help a person with mobility issues function. Something as simple as finding the right shoes can make all the difference for a person living with MS.

If gait difficulties do not respond to therapeutic interventions, mobility assistive devices may be useful tools to help people with MS be more ambulatory and active. This technology allows impaired individuals more independence, helps them to conserve energy, and ultimately improves their quality of life. There are a number of different types of mobility aids that can help. Different devices may be more beneficial, depending on the circumstances. For example, one may be needed at home and another when one is out and about. One device may be necessary for stairs and another for walking on a flat surface. Deciding which to use should be based on an individual’s needs and comfort level, as well as convenience and cost. This decision should be made with the help of one’s physician and an assistive technology professional, like a physical therapist (someone who has experience in assessing and selecting assistive devices for people with MS).

An orthosis, or brace, can help an individual with muscle stiffness or decreased muscle tone have more control when they walk. Orthoses are available in many types and styles. An ankle foot orthosis (AFO) is most commonly used to support the ankle and foot and prevent foot drop. Foot drop is a condition caused by
weakness or paralysis of the muscles involved in lifting the front part of the foot while walking. An AFO helps to prevent the toe from dropping and catching on the ground, thus providing for adequate foot clearance mid stride. AFOs are available in different materials (metal, plastic, or carbon fiber) and can be custom made. Some are solid and some have ankle hinges. They are worn inside the shoe and, depending on the material they’re made of, can be made to remain hidden from view. A hip flexion assist orthoses (HFAO) is a mobility aid for those experiencing difficulty walking due to weakness in the hip muscles. This device is designed to improve gait by assisting with hip and knee flexion, as well as lifting the foot mid stride. An HFAO consists of a waistband and two dynamic tension bands that attach to the shoe and may be worn over or under clothing.

**Functional electrical stimulation** (FES) is a technique that helps with foot drop, as well as balance issues. It can also be used to improve an individual’s ability to stand or walk during rehabilitation treatment. FES uses mild electrical currents to stimulate the nerves that activate weakened or paralyzed muscles. An FES device consists of a lightweight battery-powered control box (about the size of a pack of cards) and electrodes that are usually worn continuously while an individual is active. Surface devices, as the name implies, are worn on the surface of the skin. For foot drop, the device is worn below the knee so the electrodes can stimulate the nerve that goes to the muscle that would normally lift the front of the foot. At the moment the foot is about to lift up and swing forward in the gait, the FES device stimulates the nerve and lifts the foot. The stimulation stops when the foot hits the ground again. Two commonly used surface FES devices are the WalkAide and the NESS L300. Parts, or all, of an FES device can be implanted under the skin for added convenience, or to avoid any skin irritation that may occur with surface devices. Examples of implantable FES devices include Actigait and Neurostep.

A number of walking aids with varying bases of support are available for those with mild to moderate ambulatory or balance issues. Individuals who have more disability generally use devices with a wider base of support, thereby decreasing their risk of falling. Canes are designed to help those with mild issues by more evenly spreading the weight on the hips to mimic the distribution that would occur in a normal gait. There are two major types of cane. Single-point canes have a single point touching the floor. Multi-point canes have multiple support points, which make them able to stand on their own and provide additional support for the user. A quad cane has four points touching the floor. Canes are readily available in different lengths, styles and materials. They also come with different handles and adjustability (some can be folded when not in use). Trekking poles serve a similar purpose. A trekking pole is a lightweight walking stick that is similar to a ski pole, but it’s made for walking. In 2015, researchers at Rowan University conducted the **Trekking Poles to Aid Multiple Sclerosis (TRAMS)** study. Participants in the study reported greater self-esteem and less fatigue, and experienced better walking function when using a trekking pole compared with either a straight or a quad cane. Crutches provide more balance than canes during walking by providing a wider base of support. Two types of crutches are available, each of which is named by its location of use. Underarm crutches fit into the armpit during use. Forearm, or Loftstrand, crutches have arm cuffs that cradle the forearms, and handgrips for support. For those with moderate gait abnormalities, walkers provide an...
even wider base of support. Walkers come in two basic types, each with many different variations. A standard walker has a basic aluminum frame that folds, is height-adjustable, and is available with or without wheels. A walker without wheels must be lifted and moved forward as an individual walks. A wheeled walker, or rollator, can be pushed forward without lifting. A wheeled walker may have additional features including a seat, basket, or handbrakes. It’s important to note that changes in posture may occur when using crutches or walkers, as one must lean forward for support. Canes, crutches and walkers must be adjusted to the correct height to avoid issues with back, shoulder, elbow, and/or wrist pain.

Wheelchairs and scooters provide mobility from a seated position for those who are experiencing ambulatory/more severe balance difficulties and frequent falls. There are three types of wheelchair. Manual wheelchairs move by the user pushing the rims of the wheels. Power wheelchairs are battery-driven and are available in three types according to the location of the drive wheels (rear-wheel, mid-wheel, and front-wheel). Seating options range from basic captain-style seats to custom seat cushions and backrests with power functions. The standard control mechanism for a power wheelchair is mounted on one of the armrests, however this is customizable. The controls typically consist of a joystick and set of buttons that change the function being controlled by the joystick. These functions may include wheelchair movement, tilting or reclining the seat, and elevation of the seat or footrest. Pushrim-activated power-assist wheelchairs (PAPAWs) are a hybrid between a manual wheelchair and a power wheelchair. A person using a PAPAW continues to hand propel the wheelchair using the push rims, however, motors in the hubs of the wheels amplify the user’s strength, making it easier to move. Scooters are battery-powered three or four-wheeled devices that turn on and off with a small key. They operate by pressing a forward and backward switch (tiller) and the seat typically swivels sideways to allow easier access. Scooters are often less desirable than power wheelchairs because they tend to be less stable during turns and are more difficult to drive and turn in small spaces. They also have fewer seating options to accommodate users with specific needs.

As mentioned in our May 2018 newsletter, the Multiple Sclerosis Association of America (MSAA) has an Equipment Distribution Program that offers products designed to help those with balance, coordination, and mobility issues. Items distributed through this program include canes, walkers and wheelchairs. MSAA ships products to qualified individuals free of charge.

In addition to these standard mobility aids, a number of innovative devices currently under development may accommodate the mobility needs of people with MS in new and exciting ways. Robotic devices are one of these emerging technologies. One such device, typically used in physical therapy, is the Ekso Bionics exoskeleton training system. This wearable bionic suit enables individuals with any amount of leg weakness to stand up and walk with a normal gait. The user's weight shifting activates sensors in the device, which in turn trigger
battery-powered motors to drive the legs to take steps. Another example of this new technology is the H2 Robotic Exoskeleton, developed by researchers in Spain. In a preliminary study, the H2 was shown to be safe and effective in helping stroke victims regain the ability to walk. The Kickstart system is a wearable device designed to help individuals regain walking and other functional abilities, both in physical therapy and in daily life. The hope behind using this type of technology is its repeated use may trigger the brain to form new neural connections that slowly increase movement and functionality in paralyzed or weakened legs, also known as neuroplasticity.

Researchers in London and Singapore have developed a wheelchair that may be easier to use than a regular powered wheelchair because of its shared control system. This new technology is in part controlled by the user, and also by pre-programmed paths. An assistant walks the chair through the desired pathway while the chair records the path. The user controls speed, starts, and stops, as well as any deviations needed to avoid obstacles on the pre-programmed path. The wheelchair returns to the path once the user steers around the obstacle and relinquishes control. The benefit of this approach is the user doesn’t need to worry about navigation or planning a path, they only need to focus on avoiding obstacles and speed control. If the user wishes to navigate in new areas, new paths must be created.

For individuals with limited dexterity, the joysticks and switches on power wheelchairs can be quite difficult and sometimes painful to use. To address this, researchers are developing control systems that can be operated by parts of the body other than the hand. For example, investigators at the Georgia Institute of Technology are working on a Tongue Drive System. As the name implies, this system is controlled by the position of the user’s tongue. Sensors in a magnetic tongue stud relay the tongue’s position to a headset, which then executes up to six commands based on the tongue position. The Tongue Drive System holds great promise for individuals who have lost the use of their arms and legs. Brain Computer Interfaces (BCIs) are another emerging method that may allow a person living with paralysis to control a motorized wheelchair through thought alone. BCIs read signals from the brain and use computer chips and programs to translate the signals into action. Researchers in Germany designed a BCI-controlled wheelchair and tested it in 15 healthy subjects. Their results suggest BCIs are feasible for wheelchair control, however data also revealed a number of design issues that require further modifications and study.

Wheelchairs designed for indoor/outdoor use on a wide variety of terrains (including climbing stairs) are also under development. In 2003, Johnson & Johnson’s Independence Technology Division manufactured and sold the first iBOT 3000 mobility system. This revolutionary four-wheel-drive wheelchair could navigate stairs, curbs, and other varied surfaces. It could lift a seated user to standing height by raising up and balancing on two wheels, and travel in this mode by using sensors and gyroscopes to maintain the chair’s balance. The original iBOT was a huge
success, however it was discontinued in 2009 because of slow sales due to its high cost and lack of insurance coverage. A 2016 press release suggests that the next generation of iBOT motorized wheelchair is under development. Track chairs are a new type of power wheelchair that uses a combination of wheels and a caterpillar track to move. French researchers tested one such device, the TopChair, in 25 people with spinal cord injury. Results showed all participants were able to successfully operate the device indoors and outdoors. However, it’s important to note that no studies have evaluated the benefits of the TopChair in people with MS.

In 2007, Canadian researchers investigated the use of the Segway to assist those with mobility issues. Segway riders stand on a small platform supported by two parallel wheels while holding onto handlebars above the platform. A twist grip on the left handlebar is used to steer the device. The rider leans forward or backward to move the device forward or reverse/stop, respectively. Study results suggest the Segway is a useful mobility aid for a wide range of disabilities, including MS, and subjects found the device easy to use. Another useful up-and-coming mobility aid is the Alinker. This device supports the user’s weight while walking. The Alinker allows the user to sit upright at eye level and is equipped with handlebars for added support. It is a lightweight (26 lbs) three-wheeled walking bike with an arched aluminum frame connecting two 16-inch front wheels with an 8-inch rear wheel. An adjustable seat is mounted toward the middle of the arched frame. It has a rear-wheel brake, and is designed to fold up and fit in the trunk of a car. The rear wheels can also be removed easily during transport and storage.

A wide variety of mobility aids are available to help those with ambulatory difficulties. Whether the aid is of an innovative design and features, or tried and true, user acceptance of any device is key to its success. When faced with the possibility of using a mobility aid, a person with MS may view this prospect as a failure or as giving in to the disease. Some may be concerned once they use an assistive device they will become dependent on it. Others may worry about how they might be viewed or that others will think less of them. It’s important to view a mobility aid as a tool to help maintain, or even improve independence and quality of life. These devices allow individuals living with MS to participate in their lives more fully, with confidence and in control of their body and movements. In addition, mobility aids keep those who use them safer, conserve their energy, and even prevent future problems.
Improve Your Thinking While Living With MS

Maintaining mobility is one of the top concerns for people with MS. However, a loss of cognitive function can be just as devastating. 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. Recognizing symptoms of MS-related cognitive decline is important for early intervention. Preventive strategies, such as being vigilant about medications and managing co-morbidities that may worsen cognitive symptoms (such as sleep disorders) are also key to keeping cognitive function as healthy as possible.

Assistive technology (AT) is any item that is used to improve an individual’s function at home, work, school, or in the community. Cognitive AT helps with thought processes like focus, attention, memory, organization, management or planning events/activities. There are two categories of cognitive AT, internal and external. An internal aid is a way of thinking to enhance a particular cognitive process. External cognitive aids, as the name implies, are external items or devices that assist with thought processes. For example, research shows memory loss is common in people with MS. Internal memory aids help to focus attention and give meaning to what one may be trying to learn or remember. Some helpful thought patterns may be as simple as repetition, or mental imagery (creating a picture of something in one’s mind) to help recall information. Some people also find creating rhymes or stories about what they are trying to remember, or linking things together to be helpful. Some useful external memory aids may include lists, sticky notes, white boards, diaries, or calendars. There is evidence that using a personal digital assistant (PDA) improves cognitive and daily function in people with MS. A box or bin can be placed in a central area for everyday items, such as keys or glasses, to prevent misplacing these items. Pillboxes are a useful aid to organize daily medications. Some have built-in alarms that alert individuals when it’s time to take their medicine. Cell phones are a useful external memory aid in many ways. Contact lists reduce the need to remember phone numbers. Individuals can take a picture of new people, places or things and email them to themselves with a note to help remember them later. GPS systems on cell phones (or in cars) can prevent one from getting lost. Phone apps can help people with MS stay organized, track disease activity and store medical information. As discussed in our May 2018 newsletter, MSAA has developed a free mobile app, My MS Manager™, which can collect and store the above information, and securely share it with an individual’s healthcare team. The app enables those with MS and their physicians to closely track and manage disease activity.

Research suggests that people with MS who maintain mental activity, such as reading or puzzles, are able to withstand considerable disease burden (white matter lesions or brain atrophy) without cognitive impairment. There are a number of fun ways to stimulate the brain. Games like Sudoku, solitaire, and dominoes all require some form of sequencing (arranging items in a particular order), problem solving, reasoning and mental flexibility, all of which may be affected by MS. These types of games utilize and strengthen these skills. Crossword puzzles and
Scrabble provide equal benefit with an added language component that can reinforce word retrieval. Jigsaw puzzles, hidden pictures, word/number searches, and mazes are all types of search and find games that boost visual-perceptual skills, another area that those living with MS may struggle with.

**Brain-training** websites and apps have become increasingly popular over the last few years. Brain training is based on the premise that mental stimulation can improve neuroplasticity. As we discussed in our April 2019 newsletter, neuroplasticity is the brain’s ability to form and reorganize connections between brain cells in response to new tasks. The effectiveness of brain training in boosting mental function is well documented. A 2013 study showed brain training games improve executive functions, working memory, and processing speed in young adults. Another study found three months of cognitive training led to significant improvements in attention and memory in older adults (aged 65 or older). These results suggest brain-training games may be a simple and convenient way to improve some cognitive functions for people of all ages.

**Brain HQ** is an online brain-training system that offers 29 different activities designed to “exercise” an individual’s attention, brain speed, memory, people skills, navigation, and intelligence. Each exercise adapts in difficulty, so users always train at an optimum level (where they are most likely to make cognitive improvements). A recent study, using a version of Brain HQ specifically designed for research, suggests that this type of online training program, accessed from home, can improve brain functioning in people with MS. Researchers studied 135 subjects with MS, each experiencing cognitive difficulties. Participants were randomly assigned to either a brain-training program or to a control group using ordinary computer games (word puzzles and other games). Researchers found that the subjects in the brain-training group had significantly greater improvement in cognitive function, even though those in the control group spent more time playing computer games.

There are many other websites offering free brain-training games for individuals to keep their thinking and memory sharp. These activities can be accessed online or via apps on mobile devices (smartphones and tablets). **Lumosity** offers more than 50 mini games that are designed to train five cognitive functions: speed, memory, attention, flexibility, and problem solving. At sign-up, users complete a "fit test," which measures their initial speed, attention, and memory. This provides insight into the areas of cognition that require the most attention. Each day going forward, Luminosity sends a reminder to complete a brain "workout," which involves 3-5 mini games. The games on **CogniFit** are also designed to improve a wide variety of cognitive functions. This program offers brain-training exercises tailored to MS. Activities include puzzles and games, appropriate for all ages, focused on strengthening many cognitive processes (memory, concentration, planning, reasoning, mental agility and learning).

Some websites focus on education as a means to improve cognitive functioning. **Khan Academy** is a nonprofit organization whose mission is to provide a free, quality education to anyone, anywhere. Khan Academy offers practice exercises, instructional videos, and a personalized learning dashboard that allow users to study at their own pace. Their app
allows individuals to download more than 4,000 videos on a wide variety of subjects. These resources are available in more than 36 languages. A recent study suggests bilingualism has a positive effect on cognition later in life, not just for those living with MS but in general. Results indicate this benefit occurs in individuals who speak two or more languages, even those who acquire a second language in adulthood. Duolingo is a platform that includes a language-learning website and app, as well as a language proficiency assessment exam. As of January 2019, Duolingo offers 85 different language courses in 24 languages.

Charge Your Brain is another brain-training app that is available on the iTunes App Store. It’s described as a “colorful brain-teaser with lots of mini games.” Each mini game is designed to train different parts of the brain and different types of memory. An interactive guide (Kate) helps users in the app. Users earn medals upon completion of each game based on how many problems they solve correctly. Research shows that exposure to art boosts intelligence and critical thinking skills. DailyArt is a free app that sends one piece of fine art every day to the user’s mobile device via a push notification. Users can explore and search a collection of more than 2,000 masterpieces, as well as read artist biographies and get information on a large number of museum collections. Users can also share the paintings with family and friends on social media or via email.

A recent study found video games targeting cognitive abilities may improve brain function in people with MS. Big Brain Academy is one such video game that offers activities targeting memory, attention, visual-perceptual skills, and processing speed. Tests are done throughout the game in order to hypothetically measure the player's “brain mass.” (This is not a literal measurement, but rather a parameter within the game.) According to the game, the heavier the brain, the smarter the brain is or the better its reaction time. At the beginning of the game, users take a test to determine the appropriate difficulty level of activities. One can then choose from a variety of puzzles from five categories: logic, reasoning, math, visual, or memory. Brain Age is a series of brain-training video games developed and published by Nintendo. Brain Age also features a variety of puzzles, such as stroop tests, mathematical questions, and Sudoku puzzles, all designed to help keep certain parts of the brain active. Japanese researchers found that elderly participants who played Brain Age for four weeks experienced improvements in executive functions, such as sequencing, problem solving, reasoning, mental flexibility, and processing speed. Mini-games included with Brain Age also target other cognitive processes, such as memory, attention, and visual-perceptual skills.

A new technology called transcranial direct current stimulation (tDCS) has been recently shown to improve some of the symptoms of MS. During the tDCS procedure, a low-amplitude current travels through a set of electrodes, which are placed on a person’s scalp. The electric current stimulates the brain, thus enabling neurons to signal to each other more easily. This, in turn, improves neural connectivity and hastens the learning process. Researchers from NYU conducted a study during which 45 subjects with MS participated in a brain-training program,
playing computer games to improve cognitive skills, such as problem solving, attention, information processing, response time, and other working memory skills. 25 subjects used tDCS during these activities, and a control group of 20 participants underwent cognitive training without tDCS. Data showed the tDCS group had higher cognitive scores and significantly improved response times than the control group. These results suggest that tDCS, performed under a supervised treatment protocol, may provide an exciting new treatment option for people with MS struggling with cognitive symptoms. There are a number of tDCS products available for purchase. It’s important to note that these devices are not standardized. There are many factors to consider that may vary widely between devices, including electrode size and positioning, intensity and duration of stimulation, number of sessions per day, and the interval between sessions. This technology should only be considered in consultation with one’s physician.

There is mounting evidence that mental stimulation holds great benefit for people with MS. Cognitive exercise is similar to physical exercise in many ways. Challenging oneself is key to seeing benefits. Furthermore, it is important to workout consistently to maintain or increase any improvements made. There are many different ways to engage in cognitive exercise and many types of brain training games available online, via smartphone apps or as traditional board games. Before beginning a cognitive exercise program, it’s important for individuals with MS to first have any difficulties they may be experiencing addressed by a healthcare professional, and seek their recommendation for appropriate activities or aids that may be of benefit.

**Telemedicine – Revolutionizing MS Healthcare**

The World Health Organization (WHO) refers to telemedicine as “healing from a distance.” It is the remote delivery of healthcare services, such as health assessments or consultations, using telecommunications technology. Telemedicine allows healthcare providers to evaluate, diagnose and treat patients remotely, without the need for an in-person visit. It can be used for a wide variety of health services, including MS care. Telemedicine is a growing trend in the healthcare industry. Many patients consider it an energy, time, and cost saving way to see a clinician for minor and non-urgent medical needs instead of going to a doctor’s office or emergency department. Healthcare providers see it as an efficient way to provide care to those who may live in rural areas, or have difficulty making it to an appointment. Despite these many benefits, there is much controversy surrounding the practice of telemedicine.
The concept of telemedicine began in the 1800’s with the invention of the telecommunications technology, including the telegraph, telephone and radio. Telemedicine was used as early as the Civil War, when things like medical consultations and ordering medical supplies were conducted via telegraph. In the 1950’s, the practice of telemedicine evolved further. Medical staff transmitted radiologic images by telephone between health centers in West Chester and Philadelphia, Pennsylvania. A Canadian doctor built a teleradiology system based on this technology that was used in and around Montreal. In 1959, doctors at the University of Nebraska were able to transmit neurological examinations to medical students across campus via a two-way interactive television. By 1964, they had built a telemedicine link that allowed them to provide health services at Norfolk State Hospital, 112 miles away from campus. With the rapid changes in technology over the last few decades, telemedicine has transformed into a complex integrated service used in hospitals, homes, private physician offices, and other healthcare facilities. Using modern technology and telecommunications, doctors can visit their patients in a virtual manner, usually over live video or through still images captured and saved for their reference on a computer. Simple user-friendly medical devices that can take vitals, monitor glucose levels, or measure blood pressure enable individuals to gather needed medical information at home for a doctor’s analysis.

People are starting to use these devices, and a wide variety of mobile health apps to monitor and track their health. Physicians can gather essential medical information and make a diagnosis without patients stepping foot in a doctor’s office.

Telemedicine was originally created as a way for physicians to treat patients located in remote places, or in areas with shortages of medical professionals. While telemedicine is still used in this way today, it’s increasingly becoming a tool for convenient medical care. Virtual healthcare kiosks are available at some retail stores where a customer can use a touchscreen computer to connect by a secure video link to a doctor. Physicians provide a wide range of healthcare services remotely, including sharing medical information, conducting follow-up visits and second opinions, chronic disease management, medication management and post-hospitalization care. Telemedicine is a valuable tool in disease prevention. Weight loss and smoking cessation are key to reducing heart disease and a host of other conditions. This new technology allows providers to connect with patients to make sure they get the support they need to be successful. Some innovative districts are using telemedicine to conduct remote visits for children that become ill at school. Telemedicine software is also used to provide support to assisted living facilities, where problems frequently occur off hours making hospitalization the only option even for less urgent issues. With the availability of telemedicine software, on-call doctors can more readily conduct a remote visit to determine if hospitalization is necessary. Telemedicine is used to divert patients from overcrowded emergency rooms by having them see a remote physician first, and proceeding to the ER, if necessary. Paramedics use this new technology to see the capacity of an ER in real-time instead of heading to the hospital and being diverted later. In the recent past, telemedicine has been used during disaster relief efforts. When hurricanes Harvey and Irma occurred in 2017, healthcare professionals provided both emergency and routine health video visits.
Often times, the terms “telemedicine” and “telehealth” are used interchangeably. However, there is a distinction between the two. Telemedicine refers specifically to remote clinical services. Telemedicine is considered a subset of telehealth, which includes both remote clinical service delivery and nonclinical services such as continuing medical education, provider training, and administrative meetings.

Telemedicine can be classified into three main categories. **Remote patient monitoring** (RPM), as the name implies, allows healthcare providers to track a patient’s vital signs and other health data from a distance. This makes it easier for patients and physicians to maintain close communication and manage chronic diseases, like MS. The recent rise in wearable technology and mobile medical devices has made RPM easier. Patients have better, cheaper, more accessible tools at their disposal for tracking and reporting health information. **Store-and-forward, or asynchronous**, telemedicine enables healthcare providers to securely share patient medical data (lab results, images, videos, records) with a provider at a different location online. This type of remote care is typically used when a provider needs to consult with a specialist about a patient’s diagnosis. The asynchronous term refers to the fact that the consulting specialist, patient, and primary doctor don’t all need to be communicating at the same time. **Real-time (or synchronous)** telemedicine offers a virtual alternative to an in-person doctor’s visit. It is a live interaction between either a health professional and patient, or between health professionals, using audio and video communication.

With telemedicine on the rise, an increasing number of companies now offer direct-to-consumer care via apps available on mobile phones and websites. These services make it possible to speak to a licensed, on-call doctor in a matter of minutes no matter where an individual might be (work, home or traveling). Many companies offer this convenient care on a 24/7 basis. Some companies offer hospitals and larger health centers access to extra clinical staff and specialists via telemedine technology. Others provide a platform for physicians to use to have virtual visits with their own patients.

There are a number of pros and cons to remote healthcare, for both patients and physicians. On the plus side, it makes access to quality care much more convenient for patients. Virtual visits ease many of the hassles of going to see a doctor, such as time away from work, travel time/expenses, interference with child or elder care responsibilities, and exposure to other potentially contagious patients. People in rural or underserved areas, as well as those with mobility issues, can obtain healthcare services that they might not otherwise be able to get. Telemedicine engages patients by allowing them to conveniently connect with their doctor more frequently. This close communication may not only enable a stronger doctor-patient relationship, but patients may feel more empowered to manage their care. Telemedicine makes it easier for providers to follow-up with patients and make sure everything is going well. It also allows providers to encourage their patients to make healthy lifestyle choices, such as smoking cessation. This, in turn, leads to better health outcomes. With this advance in technology, a medical practice or hospital system can immediately expand access to consults from specialists. Providers enjoy fewer missed
appointments and cancellations, and clinics run more efficiently. Overall, some people believe telemedicine has the potential to cut healthcare spending by reducing problems like medication non-adherence and unnecessary ER visits.

There is also a downside to telemedicine. Individuals without access to a smartphone or a computer with high speed Internet may not have access to it. As with any technology that involves transmitting personal information, like patient data, security is a concern. The required technology needs to be secure and HIPAA compliant. Providers need to be trained on how to use the necessary equipment and software. Telemedicine equipment involves some cost, as does the startup of implementing such a program. Many states require physicians caring for patients remotely across state lines to have a valid license in the state where the patient is located. This is a logistical nightmare for many doctors, and as a result some are advocating for cross-state medical licensing. Many states do not allow online prescribing without an established relationship between the physician and patient, which is presumed to be established during an in-person encounter. Critics of telemedicine argue it reduces continuity of care. Patients may see a random doctor who doesn’t know them, or their entire medical history. Some believe online interactions are impersonal. Others maintain, more often than not, physical exams are necessary to make a full diagnosis.

The American Medical Association (AMA) has a set of ethical guidelines for physicians practicing telemedicine. According to these guidelines, physicians are expected to follow the same standards they would for any in-person medical visit (code of ethics, HIPAA guidelines, documentation requirements, credentials and licensing). Specific to remote healthcare, physicians are expected to be proficient in the use of the relevant technologies and comfortable interacting with patients electronically. Providers should recognize the limitations of the technology and take appropriate steps to overcome them. They must ensure they have the information they need to make well-grounded recommendations when they cannot personally conduct a physical examination. In addition, clinicians are expected to provide patients with a basic understanding of how telemedicine technologies will be used in care, the limitations of those technologies, and what will be expected of patients for using them.

Policies for reimbursement of remote healthcare services are complicated and vary from state to state. Many have parity laws that require reimbursement for telemedicine visits the same way as if the service was provided in-person. In order to be reimbursed for telemedicine services, some states require providers to obtain patient consent beforehand. Medicare will only reimburse for certain remote healthcare services and providers. Medicare restricts the eligible locations for reimbursement to rural areas and those designated as having a shortage of health providers. Interestingly, according to Medicare, a patient’s home is not currently an eligible site from which to receive care. In addition, Medicare will only pay for certain facilities to provide services, such as a doctor’s office, hospital or rural health clinic. Medicaid reimbursement varies for each state, but most states offer some form of coverage for telemedicine services. Similar to Medicare, there are reimbursement limitations for patient settings and facilities. A summary of reimbursement policies by state can be found here.
Remote medical services are an increasing component of healthcare delivery in the United States. Recent advances in technology hold great potential for the future growth. Smart glasses and smart watches are now able to monitor patients’ health data and transmit them in real time to health professionals. Face tracking technology allows computers to read facial expressions, which may be used to monitor mental/emotional health. These technological innovations make the collection and transference of medical data easier and faster. Researchers are studying ways telemedicine can benefit people living with MS. As mentioned in our April 2019 newsletter, the Patient-Centered Outcomes Research Institute (PCORI) has funded three studies to determine the effectiveness of telemedicine in helping people with MS improve their level of physical activity and deal with fatigue. Researchers at the University of Michigan are conducting a study using a wrist-borne sensor to measure the effects of two different treatments for fatigue: cognitive behavioral therapy delivered by phone and the wakefulness-promoting drug, Modafinil. Another fatigue study at Case Western Reserve University is evaluating the effectiveness of three different forms of fatigue management: in-person instruction during medical visits, online instructions and a telemedicine platform using video visits. Investigators at the Shepherd Center in Atlanta are comparing traditional exercise therapies at a gym or rehab center with a telerehabilitation therapy available to patients at home.

A recent study from UCSF demonstrates many benefits of telemedicine for MS providers and patients alike. Five physicians at a large MS practice and their patients were surveyed about their experience following both in-person and televideo visits. The vast majority of MS providers (96%) were satisfied with patient evaluations conducted remotely. One third of patients with MS didn’t need to take time off from work and over half didn’t need to arrange for childcare for their remote visit. Patients strongly agreed (86%) that they had achieved their goals for their televideo visits. The care received remotely and in-person was perceived as similar on all but one quality measure, which was eye contact (84% reported “extremely good” eye contact during their remote visit compared 99% for in-person visits).

Dr. Mitchell Wallin has overseen a number of clinical studies on the use of telemedicine in MS care. One study suggests a visit conducted via telemedicine is comparable to an in-person visit. Specifically, data showed the difference between neurological exams conducted remotely and in person are comparable to those conducted by different neurological examiners directly assessing the same patient. In Dr. Wallin’s words, “We used high end cameras with large plasma screens so you could see really well. We did the study in two separate clinics, one was in Washington, DC and one was in Baltimore. We had a nurse practitioner or physician’s assistant doing the exam. They were the tele-presenter. I was one of the people at one end and another MS neurologist was on the other end. An independent person did a live EDSS and we did the remote one. We correlated all of the functional systems. Bottom line is it correlated pretty well… We did the same thing with lower end cameras that mocked the home environment. There was a tech that helped with the exam. Obviously we can’t do every single aspect of the exam, but we did get pretty good correlation there, too. With some help, you can actually do pretty well in the home. It’s not the same as being live, but I think it gives you much more than a telephone call.” Researchers in Israel have also shown that telemedicine is an effective way to monitor people with MS at home. Dr. Wallin’s research team has also
studied the feasibility of using home telehealth monitoring to improve clinical care and promote symptom self-management among veterans with MS. Data indicate telemedicine monitoring is both feasible and well received (87.5% of subjects rated their experience with telemedicine as good or better).

A recent commentary concluded telemedicine has the potential to transform the future of medicine in both rural and urban settings by improving access to medical care and providing a more affordable way to deliver it. Authors suggest low reimbursement rates and lack of interstate licensing are the main obstacles limiting its widespread use in the United States. In spite of this, demand for telemedicine will likely continue to rise. When asked if he thinks telemedicine is the future of MS patient care, Dr. Wallin states, “The short answer is yes. I think we have to figure it out. Every disease has its niche for this. MS involves so many subspecialties. It’s not just neurology, but patients have to interface with physical medicine doctors and urologists. There may be certain areas where telehealth will work or will be a good fit for some of these visits. I think people are pretty creative. As the technology gets better, there will be more creative ways of assessing people remotely.”

Repository Spotlight – DxTerity, Managing MS Through Genomic Monitoring

Genomics may play a key role in understanding how to effectively treat autoimmune diseases like MS. Genomic studies look at how an individual’s genes (DNA) interact with their environment, or the medications they may be taking. The information encoded into an individual’s genes is expressed via transcription of the genetic information into RNA. Thus, while DNA generally stays the same throughout one’s lifetime, a person’s RNA profile can change in response to these external factors (like the environment or medications) and provide important information on what is happening in the body. Collecting samples from people over time and studying their RNA profile is helping researchers develop better ways to monitor and treat diseases like MS. There are numerous MS treatments available. The ability to predict how an individual will respond to a given treatment through RNA monitoring could help clinicians and those living with MS better manage, and even get ahead of, the disease. DxTerity, a genomics company, is developing a low-cost, user-friendly device to collect a small amount of blood for RNA sequencing. People with MS will be able to use this device at home and mail their sample to a lab for analysis. This information may help physicians monitor disease activity, and may make it
easier to make more effective treatment choices based on an individual’s biology. This innovative research to develop at-home genomic monitoring builds off of the work of a large number of researchers who focus on disease-associated transcriptional changes. Several studies using samples from the ACP Repository have focused on transcriptional changes and have advanced this field of study. Researchers hope these new advances in technology will lead to more groundbreaking opportunities for advancing and accelerating research into MS!

**iConquerMS™ Spotlight – Dr. Mitch Wallin, Washington, D.C. VA Medical Center**

iConquerMS is partnering with the National MS Society and Dr. Mitch Wallin (director of the Washington, D.C. VA Medical Center) to conduct a thorough evaluation of MS telehealth use in the United States. We will soon be conducting a survey of the iConquerMS community on their awareness, utilization, and experiences with telehealth, including barriers that may stand in the way of telehealth becoming an integral part of MS healthcare in the United States. ACP and Dr. Wallin plan to use this information to develop and administer a nationwide survey of people living with MS to better understand utilization patterns across a larger area and a more diverse population. As a member of iConquerMS, your responses to the telehealth survey will help us better understand the types of people who use or would like to use this new technology and may one day help revolutionize MS care! This study is just one of the many ways iConquerMS is facilitating and accelerating research on topics of importance to people affected by MS. If you are not already a member, please consider [joining iConquerMS]. Already a member? Stay tuned for new opportunities to participate in research!

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