Dear Friends,

Of the more than 200 types of cells in the human body, stem cells are the most versatile. They can replicate and develop into every organ and tissue in the body. A stem cell therapy is a treatment that uses stem cells, or cells that come from stem cells, to replace or to repair a patient’s cells or tissues that are damaged. Researchers are making significant progress in their work to better understand the use of many types of stem cell treatments for slowing MS disease activity and for repairing damage to the nervous system. However, there is still a lot to learn about stem cell treatments. Learn more about these pioneering treatments, their potential benefits, and limitations.

Richard Cohen’s network television news career spanned 20 years, during which he covered wars and politics for ABC News, CBS News and CNN. He received numerous awards in journalism, and is a New York Times bestselling author. Richard was diagnosed with MS when he was 25 years old. The lack of effective treatments for progressive MS and caring physicians over the course of 4 decades left him with little to anticipate other than a steady decline. In 2014, Richard received an autologous stem cell injection for his MS alongside a clinical trial. This, coupled with a caring neurologist, has enabled him to have hope for the future. Richard shares his experience with stem cell therapy, and insight into the concept of “hope” and its relationship with chronic illness in his new book, *Chasing Hope*. Our second article sheds light on the author and his latest literary work.
David Bexfield was diagnosed with MS when he was 37 years old. At the time, he was managing editor and co-owner of Nissan Sport magazine. A firm believer in staying fit and active, he also enjoyed participating in a wide variety of sports. Three years after he was diagnosed, Dave’s MS kicked into overdrive and he experienced an alarming progression of symptoms. In 2010, Dave enrolled in a hematopoietic stem cell transplant trial as a last-ditch effort to stop the free fall. Read more about Dave’s experience with stem cell therapy, and the many ways he works to spread hope and inspiration to others living with MS.

In his column this month, Dr. Farren Briggs discusses movement rehabilitation and MS. Our Repository Spotlight also features Dr. Briggs’ work studying genetic variations and modifiable lifestyle factors affecting age of onset, symptoms patterns at onset, and MS progression.

Our iConquerMS Spotlight highlights REAL MS™ (Research Engagement About Life with MS). The information collected in this study will play a pivotal role in accelerating research to determine ways to personalize clinical care by identifying factors that affect progression and treatment outcomes for MS patients.

We appreciate your support and hope that you are enjoying these pleasant days of Spring.

The Accelerated Cure Project Team

**Stem Cells – The future of medicine?**

There are more than 200 types of cells in the human body, for example blood cells, muscle cells and nerve cells, to name a few. Each cell type has a different makeup that is appropriate for its function. Stem cells are the foundation for every organ and tissue in the body. There are many different types of stem cells that come from different places in the body or are formed at different times in our lives. Some only exist prenatally (embryonic stem cells), while others are found during fetal development and remain in our bodies throughout life to repair tissue damage and replace lost cells (adult stem cells).
Stem cells are defined by two characteristics. They can self-renew (make copies of themselves) and differentiate (develop into more specialized cells). Beyond these two things, stem cells differ a great deal in their abilities and function. Embryonic stem cells are pluripotent, meaning when cultured they give rise to all of the body’s cell types. Others (adult stem cells) are referred to as multipotent, meaning they can generate a few different cell types (generally in a specific tissue or organ).

Embryonic stem cells, as the name implies, are the cells of the developing embryo. They are obtained from the blastocyst, a ball of cells that forms three to five days after an egg cell is fertilized by a sperm. When scientists extract embryonic stem cells and grow them under special laboratory conditions, they retain the ability to give rise to all tissues and organs in the body. These cells are incredibly valuable as a renewable resource for studying normal development, disease processes, and treatments. However, the ethical considerations surrounding their use are considerable.

Adult stem cells are more specialized than embryonic stem cells. Typically, they produce the different cell types for the specific tissue or organ in which they are found. For example, hematopoietic stem cells, which are found in bone marrow and blood, are capable of producing all of the cells that make up the blood and the immune system (red blood cells, white blood cells and platelets). Neural stem cells from the central nervous system give rise to neurons, oligodendrocytes (myelin producing cells), and astrocytes (support cells). Mesenchymal stem cells (MSCs) are adult stem cells from stroma, the connective tissue that surrounds tissues and organs (sometimes called stromal cells). They are found in several places in the body, including the bone marrow, skin, and fat tissue. MSCs can differentiate into a variety of cell types. Some tissues and organs in the body contain small reserves of stem cells to replace cells from that tissue that are lost through normal day-to-day living or injury.

Induced pluripotent stem cells (iPSCs) are adult, tissue-specific stem cells that have been modified in the lab and converted into cells that behave like embryonic stem cells. While iPSCs share many of the same characteristics of embryonic stem cells, including the ability to give rise to all the cell types in the body, they aren’t exactly the same. Researchers are studying these differences and various ways to create iPSCs to learn more about their function and potential use.
A stem cell therapy is a treatment that uses stem cells, or cells that come from stem cells, to replace or to repair a patient’s cells or tissues that are damaged. The stem cells might be administered intravenously, via lumbar puncture, or transplanted into the damaged tissue directly. An autologous stem cell treatment is one in which stem cells are harvested from a person, stored and given back to that same person. An allogenic treatment is one in which the donor and recipient of the stem cells are different people. The list of diseases for which there are approved stem cell therapies is extremely small. There are no approved stem cell treatments for MS at this time, however there is exciting progress being made as researchers study the potential of different types of stem cells to slow MS activity and to repair damage to the nervous system. It’s important to note that much more research is needed before cell-based therapies become a viable MS treatment option.

Several stem cell-based approaches to treat MS are being tested in clinical trials. Autologous Hematopoietic Stem Cell Transplantation (HSCT) is an anti-inflammatory therapy. The goal of HSCT is to reset the immune system, which is responsible for damaging the brain and spinal cord in MS, and stop the inflammation that is responsible for disease activity. A person undergoing HSCT to treat MS is given some form of chemotherapy to stimulate the production of bone marrow stem cells and promote their release into the blood. Stem cells are then obtained from a blood sample and stored for later use. During the next step of treatment, the individual is usually hospitalized, and given a powerful mix of chemotherapies to kill or suppress immune cells throughout the body. The individual is usually also given antibiotics to help combat infection. The stored stem cells are then infused intravenously in hopes that the immune system will rebuild itself (a process that usually takes 3 to 6 months). After recovery, it is hoped that the newly formed immune system will function more normally. The studies to date suggest HSCT has potent, durable benefit in relapsing MS. However, there are substantial safety issues that need to be resolved and financial costs involved.

Clinical studies are currently underway to test the benefit of MSCs to repair the nervous system, specifically the myelin (a process called remyelination). This approach is similar to HSCT, except that the individual’s immune cells are not destroyed or replaced. Instead, a person’s own MSCs are isolated from their bone marrow or blood,
multiplied in the lab, and then re-introduced in greater numbers into their body, either intravenously or via lumbar puncture. MSCs promote repair by stimulating oligodendrocyte progenitor stem cells (which develop into cells that make myelin) that are already present within the nervous system. They also have the ability to stimulate the formation of new blood vessels. There are some theories that one of the processes that may contribute to progressive MS is insufficient blood supply. Clinical trials with MSCs have had promising results. However, a number of important questions have arisen concerning the type of cells that work best, delivery methods, technical aspects of cell production, safety issues and actual effectiveness. More research is needed before this approach can be used more generally.

One exciting avenue of research is the use of iPSCs for therapeutic purposes. In this approach, cells are obtained from an individual, for example from a skin biopsy. Using a series of genetic reprogramming techniques, they are turned into stem cells that can generate any type of human cell needed. A potential advantage of this approach is the reduced possibility the cells will be rejected by the person’s immune system. This approach also bypasses possible ethical concerns surrounding the use of human embryonic stem cells. However, this research is still in its early stages.

Researchers are also exploring how neural stem cells might be used to replace the neurons and oligodendrocytes (myelin-forming cells) lost during the course of MS. This method shows promise, but there are a number of practical issues that need to be overcome. In addition, neural stem cells are typically harvested from embryonic or fetal brain, which raises the ethical issues surrounding the use of this tissue.

Exciting research is underway and significant progress has been made to better understand the potential of many types of stem cell treatments for slowing MS disease activity and for repairing damage to the nervous system. However, there is still a lot to learn about them. The media sometimes exaggerates the benefit of stem cell treatment and clinics often promote unapproved treatments to chronically ill or seriously injured patients. Patient testimonials and other marketing provided by clinics may be misleading. Beware of clinics that broadcast this language to market their treatments, instead of science-based evidence. It’s important to watch for stem cell treatments offered without regulatory approval, or outside of a legitimate clinical trial. The National Institutes of Health maintain a database of clinical trials that patients and families can search for approved, actively recruiting studies. As stem cells come from different places in
your body and have different functions, be wary of clinics offering treatments with stem cells originating from a part of your body unrelated to your disease or condition, or that offer the same cell treatment for a wide variety of conditions or diseases. Unless they are related, different diseases would be expected to have very different treatments. Be wary of claims that stem cells will somehow just know where to go and what to do to treat a specific condition as they require careful instruction to become the specific cells needed to regenerate diseased or damaged tissue. If not properly directed, these stem cells may overgrow and form tumors. It’s important to remember that autologous stem cell infusions or transplants are not automatically safe. Even though the risk of rejection is lower, the processes by which the cells are acquired, cultured, and then reintroduced into the body carry risks. Steer clear of clinics that gloss over or minimize these risks.

If you are considering stem cell therapy, it is important to discuss it and other options with your physician and other trusted members of your healthcare team before deciding on a course of treatment. Confirm that there is good scientific evidence that the treatment is safe and effective. Be sure that the providers have approval from an independent ethics committee, such as an Institutional Review Board (IRB), to make sure the risks are as low as possible and are worth any potential benefits, and that your rights are being protected. There should be a protocol that outlines the treatment in detail, and a consent form that clearly explains the details of the process, including the risks involved. You should have the opportunity to ask questions, should you have any, and only proceed with treatment when you are satisfied with information provided and have given permission to proceed.

Stem cell research holds tremendous promise for medical treatments, but scientists still have much to learn about how they work in the body and their capacity for healing. Numerous clinical trials are underway to determine what the optimal cells, delivery methods, safety, and actual effectiveness of these current experimental therapies might be for people with different forms of MS.
Richard Cohen – “Keeper of My Own Flame”

Richard Cohen’s network television news career spanned 20 years, during which he covered wars and politics for ABC News, CBS News and CNN. He received numerous awards in journalism, including three Emmys, a George Foster Peabody and a Cable Ace Award.

Richard learned that his father and his grandmother had multiple sclerosis (MS) when he was 19 years old. A few years later, he suddenly became disoriented at work and dropped a coffee pot. The same day, he tripped off a curb and his leg went numb. He learned that he, too, had MS when he was 25. "There's an expression ‘diagnose and adios’ because really there were no treatments of any kind," says Richard. His father advised him to “suck it up and keep going.” Since his MS diagnosis, Richard has also had two bouts of colon cancer, both of which required invasive surgery.

Richard is married to journalist, Meredith Vieira, with whom he has three grown children. When he met Meredith in the early '80s, his MS symptoms were barely noticeable, except for his failing eyesight. On their second date, he told her about his condition. They decided long ago that, while MS may affect their life together, it would not define it. Their ability to look at things with a sense of humor has carried them through many hardships in their journey together with MS.

Richard and Meredith didn’t tell their children about Richard’s diagnosis until the night they witnessed their father fall down a flight of stairs and their oldest son started asking questions. They openly talked about MS with their children, but focused more on normal activities. In Richard’s words, “We were very understated, as reassuring as we could be without being dishonest. Once you create a culture of openness in the house, they’re not afraid to ask questions … it all becomes very casual and second nature.”

MS has affected Richard’s vision, voice, balance, strength, and coordination. After living with MS for more than four decades, he is legally blind, has trouble walking, and difficulty using his right side. For the Cohen’s, MS is a “family affair.” In Richard’s words, “everybody in the family is affected by MS. Everybody in the family somehow shares MS. Because it can be so
limiting for the sick person, very often the rest of the family tries to help as best they can and everybody gets involved.” Reflecting on the nature of chronic illness, Richard states, “it’s an odd thing because, even with a loving family surrounding you… there’s something very solitary about illness. I’m not contradicting myself here, it is a family affair, but there’s something very lonely about being sick. It is not anybody else who is going to suffer with it, only you feel the physical effects. Only you feel the fatigue, or the pain, and in the end we really are alone with it. Having said that, it’s still wonderful to have a family around you just because they become part of the battle.” Now that his children are grown, Richard shares that his children watch over him. “They’re just very tuned in to it … on the one hand you don’t wish it on your children, and on the other hand I really do believe that kids become better persons for growing up in a family with illness. They learn very early that life is not fair. They understand, on a very basic level, that it can be painful. They’re fully aware that they are in a position to help and I think it just becomes second nature to them… So, it’s not entirely just the ‘down’ side you’ve got to deal with. I think there’s an ‘up’ side, too.”

When asked how he best copes living with progressive MS, Cohen states, “There’s an inevitability to the journey because it’s a one way trip. You don’t get better and slowly get worse, so I think you’ve just got to come to grips with the fact that things are going to deteriorate. It doesn’t mean that it’s going to happen at any particular rate of speed. It doesn’t mean that tomorrow is the end of the world. It’s just a fact of life you’ve got to deal with … You’ve got to learn to rise above the difficulties, the physical impediments that lie before you and find a way to soar… to lift yourself up … to be bigger than your disease … to do something with your life … to live gracefully … to be a good person. This may all happen more because of the illness than anything else.” According to Richard, another aspect of MS is learning to live with how people perceive him. In his words, “I use wheelchairs at airports or very large places and people don’t want to deal with you. People don’t see us. They see the wheelchair. They don’t see the person in the wheelchair.”

Richard is the author of two New York Times bestsellers. *Blindsided* is a revealing memoir detailing his struggles with MS and cancer. *Strong at the Broken Places* follows the lives of five individuals living with serious chronic illnesses, delivering the message that we are all stronger than we think.
Even though Richard found ways to cope with and rise above illness, he rarely thought of himself as having “hope.” The lack of any meaningful treatments for progressive MS and the lack of caring physicians left him with little to anticipate other than a steady decline. In 2012, Richard and his wife hosted and chaired a stem cell conference in Rome where scientists gathered to discuss stem cell therapy for autoimmune diseases such as MS. At the conference, Richard met Dr. Saud Sadiq of the Tisch Multiple Sclerosis Center of New York. Meeting Dr. Sadiq enabled him to look at his future differently. Dr. Sadiq’s work focuses on how to utilize the potential of stem cells in trying to repair diseases like MS. He received approval for a clinical study in which stem cells would be collected from patients, transformed into brain stem cells and injected back into patients’ spinal fluid in hopes of repair and restoration of function. Richard was invited take part in the trial, which opened him up to the possibility of hope that he might get better. In the end he didn’t qualify for the trial, but he received the same treatment as those that did.

Richard shares his experiences with stem cell therapy and insights into the concept of “hope” in his new book, Chasing Hope. This latest work is an easy and touching read that includes interviews with doctors, scientists, and religious leaders, all with the goal of understanding the relationship between illness and hope. As revealed in the epigraph by Paul Tillich, Richard feels that hope has to be sensible, “Hope is easy for the foolish, but hard for the wise. Everybody can lose himself into foolish hope, but genuine hope is something rare and great.” In Richard’s words, “I think hope as a word is thrown around and it means a lot of things to a lot of people … I think if you’re going to hope, you’ve got to be smart about it. You’ve got to be realistic about it and not waste your time hoping for things that will never come to be.” Richard’s close-knit family is a major source of support and hope in his life. He also makes it clear that while many find hope through faith, he does not. In his words, “I think hope is something that you have or you don’t have. I don’t much believe that it has to be tied to anything in particular … I think hope is organic. Hope sort of feeds on itself and it’s a way of approaching life.” Chasing Hope delivers the strong message that, no matter what the source, it’s crucial not to lose hope. When asked how he keeps his sense of hope alive, Richard replies, “I don’t think it’s something you consciously do. I think it’s something burning inside of you. Sometimes the flame is high and sometimes it’s a low flame. Generally it endures and is not extinguished. I’m happy that I’m the keeper of my own flame.”
Richard generously allowed us to tape the interview for this article. If you’d like to listen to him share his experiences and perspective, please click here. Richard also writes about his journey with MS on his blog, Journeyman. When asked the reason for this title, he states, “I’m on a journey like everybody else. The drawing at the top of the blog is someone with a cane walking toward the skyscrapers of New York. That’s sort of how I see myself. I’m a member of a big city, a large community and at the same time I’m on a solitary journey.”

Chasing Hope is available now for pre-order on Amazon and will be available at bookstores everywhere on May 1, 2018.

David Bexfield – “There is most definitely hope, never forget that.”

David Bexfield lives in Albuquerque, NM with his wife, Laura. He was diagnosed with multiple sclerosis (MS) when he was 37 years old. At the time, he was managing editor and co-owner of Nissan Sport magazine, with experience in journalism, advertising, and public relations. According to David, “I was a little bit of everything when it came to writing.” In his free time he enjoyed participating in a wide variety of sports, including tennis, basketball, baseball, soccer, and Frisbee golf. He was also an avid snowboarder, hiker and cyclist.

In the spring of 2005, Dave experienced some odd symptoms - flashes in his eyesight and tightness in his chest after exercising – and his doctors could not determine their cause. One recommended that he see a neurologist. In Dave’s words, “I did what most people do – “Uh-
huh, sure,” and I went on living my life. I was feeling fine until one day in September. I was watching SportsCenter late at night … my whole right side went numb and tingly.” David went to the ER that night and within an hour was told that he might have MS. Once his diagnosis was confirmed in the spring of 2006, he started disease-modifying therapy (DMT), enrolled in a clinical trial and was monitored closely as part of the study. His MS symptoms were well managed for three years. In 2009 Dave’s MS kicked into overdrive. He failed 3 FDA-approved therapies in just 6 months. According to Dave, “I was going downhill so fast. When you have MS you know the ups and downs and you know what downhill feels like. This downhill was a free fall. I knew it and I could feel it. Every morning I would wake up and another part of me would be lost … I went from using the occasional cane, and I do mean occasional, to using a walker in 6 months and there was no respite. Even using the walker, I was struggling with that … it was blindingly fast.”

In 2010, Dave enrolled in HALT-MS, a hematopoietic stem cell transplant trial. In an effort to “reboot” their immune system, participants in HALT-MS received 6 days of high-dose chemotherapy, after which their own clean stem cells (collected before the chemotherapy was given) were re-infused. The consent form for the study listed the odds of death potentially as high as 1 in 20. When asked about this risk, Dave states, “When I signed up for HALT-MS it truly was a rescue therapy for me … All of the big guns available to me were gone, so it was stem cell transplant or bust.” He underwent extensive testing and was accepted into the study by the narrowest of margins. According to Dave, “I was almost too healthy when I applied to be in the trial. When I got in I was almost too sick.” Dave participated in phase II of HALT-MS and experienced dramatic improvement in his MS symptoms. For the first 4 years after the transplant Dave’s MS was quiet. In Dave’s words, “The benefit started up pretty darn fast. Within a couple of months I was able to walk 700 meters unaided … eventually my best day was a three-mile hiking day … but, by year three and a half or four I could tell my body was starting to slow down a little bit and some numbness was starting to creep back into my feet.” Today, walking without aids is once again a challenge for Dave and he uses a scooter and a wheelchair for distance. Reflecting on his experience, Dave says, “The trial saved my life. It did so many things for me. I have absolutely zero regrets going in to it. And I still feel good, it’s just lately my legs have been just wiped out from underneath me.”
After five and a half years of no MS medications, Dave restarted DMTs and he participated in a clinical trial testing an add-on therapy to keep his disease in check. He is also a firm believer in exercise as a form of treatment. For him, exercise and DMT have been a winning combination. When asked about his exercise regimen, “Ever since I turned 30 I’ve been working out every day pretty vigorously for an hour. Twelve to thirteen years since being diagnosed with MS, my workout routine is still pretty consistent. I take a day off each week. For the most part it’s an hour to an hour and a half of decently heavy cardio and lots of stretching … I do strength, upper body and lower body. I often will go to the gym, but not all the time. I’ll also do cardio, seated cardio, following exercise videos. I just modify whatever exercise video my wife is doing to make it work better for me. We often work out together. It keeps it fun for me and it’s an entertaining way to stay fit.” Dave’s exercise regimen helps him manage his MS symptoms. In his words, “If I don’t exercise for a week, the fatigue fog starts to roll in and it can get really challenging … but, if I get in a good, hard workout it usually keeps the fatigue at bay. Exercise research has shown that is generally true. It might not work for everybody, but for many people it does, and it works for me.”

Dave and his wife love to travel. Together they’ve visited over 50 countries and crisscrossed the world. Of late Dave travels with a wheelchair and a pair of forearm crutches. When talking about their travels, he says, “It’s been really fantastic, I’ve discovered there are a lot of ways you can make travel work, even in areas that are, for the most part, inaccessible. You have to be careful and you have to plan a little bit more, but you can go to places that you thought you could never possibly go … My favorite destination is almost certainly the last destination I was just at, because that means I got out there and I did it and it immediately becomes near and dear to my heart.”

Dave founded ActiveMSers a few days before his MS diagnosis. According to Dave, “I knew that freight train was coming, so I said ‘let’s do this’ and I started ActiveMSers.” Dave reasoned if he was having trouble adjusting to his “new normal”, other people in a similar situation would be, too. In his words, “When I got diagnosed I did what most people do when they find out they have some disease that has no cure yet – I hopped on the Internet and I read
every single thing that was published at that time … After losing lots of sleep and really gaining no information and getting more and more depressed, I figured there had to be a better answer out there … I wanted something that was fun, that was optimistic, that would be motivating and inspiring and I had the toolset to do it.”

Today ActiveMSers is a community for people living with MS to share their active passions. It is designed to help, motivate and inspire those with MS to stay as active as possible—physically, intellectually and socially—regardless of physical limitations. The website offers reviews of the latest MS aids, advice on MS exercises, inspirational stories of people with MS doing extraordinary things, and many helpful tips on living with MS. ActiveMSers also hosts a web forum for people with MS to connect, a blog in which Dave writes about his experience with MS, and publishes a free newsletter. Dave also works to encourage those with MS through social media. He shares, “I’m on the typical social media channels (Twitter, Facebook, and Instagram). In coming weeks I’ll also be on YouTube. I’ll start doing weekly, hopefully funny, little YouTube videos … It’ll be awesome, they’ll be short and they’ll be fun.”

To date ActiveMSers has helped hundreds of thousands of people with MS from around the world by offering valuable information and uplifting encouragement. Dave’s motto is “Be active, stay fit and keep exploring,” a sentiment that he most certainly lives up to. He says, “I’ve made it my goal to practice what I preach, faithfully exercising most days—stretching, cardio, strength.” When asked what he enjoys most about ActiveMSers, Dave states, “I’ve got too many favorite parts. I love interacting with my MS friends, I love the creativity and the freedom to write what I want to write … I like that I can just be myself.”

Dave is an active member of the iConquerMS community and serves on the Network’s Engagement Committee. In his words, “iConquerMS means that we finally have a patient voice in research and, as patients, as people with MS, we have a lot more power than we think. iConquerMS allows us to use that power and get us closer and ideally faster to a cure for this disease.” Referring to MS research in general, “I’ve been to a lot of research conferences and the amount of research that’s been coming out with MS has been outstanding. It’s been jaw dropping … I’m really optimistic and hopeful about the future with this disease … I have secondary progressive, that’s a really tough time of the disease to treat. I’m excited that new treatments are coming out for that. I see new research on myelin repair. Any sort of repair
treatment is encouraging and I do think there is some future in stem cell transplantation and stem cell therapy, too. I don’t necessarily think it’s the Holy Grail, but I do think it can be a valuable part of treating this disease.”

Dave has been described as living with a “stubborn defiance of MS.” He stays strong physically through exercise, and psychologically through his sense of humor. He states, “I’m funny with my friends, with my wife, with all of my MS colleagues and followers. I think humor just kind of lightens up the day and allows you to move forward with a smile on your face instead of a scowl.” With an optimistic attitude, Dave doggedly works to spread hope and inspiration to people with MS. In his words, “There’s most definitely hope, never forget that.”

Novel Movement Rehabilitation and MS
By Farren Briggs PhD, ScM

Rehabilitation is integral to comprehensive care for those with MS. However, based on the published studies, efforts to develop general guidelines has proven challenging. Fortunately, there are ongoing conversations amongst health care professionals as to the strength of evidence available.¹² This month there were two publications from the same study, which will add greatly to this active conversation on the important contributions of rehabilitation on improving outcomes for those with MS.

The two papers are based on results from the first randomized controlled trial (RCT) comparing constraint-induced movement therapy (CIMT) to complementary and alternative medicine (CAM) treatments in persons with MS (PwMS).³⁴ The RCT was designed for PwMS who had differences in disability in their upper extremities, such that one arm was mild to moderately impaired while the other arm was severely impaired. CIMT is a unique
intervention commonly used for those who have had a stroke or have other non-progressive neurological diseases. In brief, CIMT rehabilitation aims to increase use of the severely impaired arm through several hours of exercises while the less impaired arm is restrained for up to 90% of waking hours (i.e. placed in a sling, a splint, a mitt, etc., as shown in the photograph of Kenneth Lovelace, a veteran with traumatic brain injury). This RCT consisted of 3.5 hours of CIMT or CAM treatments for 10 consecutive weekdays. The CAM treatment consisted of periods of meditation and various land (i.e. yoga) and water (i.e. water tai chi) based activities. Twenty PwMS were randomly assigned to either CIMT or CAM treatments.

This first paper based on this RCT evaluated whether CIMT increased the real-world use and motor function of the severely impaired arm, and if the improvements lasted after a 1 year. After 35 hours of rehabilitation, PwMS in both groups had improvements in use of the severely impaired arm, however the increases experienced by those in the CIMT group were significantly greater. Those in the CIMT group had fairly uniform improvements, while the improvements in the CAM group were highly variable (see figure below). Most interesting is, the effect of CIMT (increased use of the severely impaired arm) lasted even after a year of follow-up.

As for the impact of CIMT versus CAM on motor function, both groups had similar positive impacts on motor function after 35 hours of rehabilitation, however, the CIMT group had significant additional improvements after a year, while the CAM group had declined motor function over time.

The second paper of the RCT investigated the impact of CIMT versus CAM on the integrity of white matter of the central nervous system. The central nervous system, which consists of the brain and spinal cord, is comprised of grey matter (neuron cell bodies) and white matter (myelinated axons of neurons, which connect different parts of grey matter and is where nerve impulses are transmitted). The researchers used MRIs to measure changes in the white matter
of the brain in both groups, and after 35 hours of rehabilitation, only the CIMT group had significant increases in white matter integrity. This increase in integrity was not correlated with increased motor function, rather by increased real-world use of the severely impaired arm in the CIMT group. Despite the small sample size, these results are very promising, suggesting that CIMT may result in positive changes in PwMS.

In summary, conducting rehabilitation studies is generally challenging, as they require time, active engagement, and a considerable amount of human resources – however, the potential impact of rehabilitation on improving the lives of those with MS considerably outweighs the study costs. I do hope we will see more studies, of larger sample sizes, investigating a diverse array of rehabilitation therapies that aim to promote wellness and optimize daily functioning in those with MS.

1. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4662703/
2. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5200850/

Repository Spotlight - Dr. Farren Briggs, Case Western University

To date over 120 genetic variants and a handful of environmental and modifiable lifestyle factors have been identified as increasing an individual’s risk for MS. Unfortunately, factors influencing the timing of onset, the types of symptoms experienced at onset, and the progression of MS are not well known. Dr. Briggs is studying genetic variations and modifiable lifestyle factors (i.e. smoking, obesity, low vitamin D levels, Epstein Barr Virus) affecting age of onset, symptoms patterns at onset, and MS disability. Dr. Briggs’ study is one of more than a hundred studies using ACP Repository samples, to date. Dr. Briggs’ research may identify new biological mechanisms underlying disease presentation and progression in MS.
iConquerMS™ Spotlight – REAL MS

In the summer of 2016, the iConquerMS initiative launched REAL MS™ (Research Engagement About Life with MS), a longitudinal study of MS during which participants periodically provide information about their experience with MS through completing surveys. In March 2018, a fourth round of REAL MS surveys were released through the iConquerMS portal. The information collected through these surveys 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. Based on the premise that “Your Health Data Has Power”, this study is just one of the many ways iConquerMS is facilitating and accelerating research on topics of importance to people affected by MS. Please consider joining iConquerMS. Every piece of data expands the pool of information that researchers can draw from. Your voice matters!

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