Dear Friends,

MS research is a dynamic field, with many brilliant minds working to better understand the mechanisms of MS so we can treat it more effectively and ultimately find a cure. Legislative changes can affect funding for these important studies, as well as other critical issues for people with MS, such as access to quality, affordable healthcare and health insurance, and the rights of people with disabilities. There are many resources available to help people with MS live their best lives, with new programs starting up regularly. Do you ever wonder how you can possibly keep up with it all? Learn more about RealTalkMS, a weekly podcast that can help you stay up-to-date on the latest news and topics relevant to the MS community.

Research shows tobacco smoke is one of the few environmental factors influencing both the risk for and the progression of MS. In our second article, Dr. Farren Briggs summarizes three recent publications on important new findings on the effects of tobacco smoke in MS.

The main focus of our March newsletter is patient reported outcomes (PROs). Doctors and researchers rely on changes in health status, or health outcomes, in order to determine a course of treatment or the direction of a research study. Health outcomes can be collected by a physician, or directly from a patient (or subject). A PRO is one directly reported from the person who experienced it, typically collected through questionnaires focusing on topics that matter most to patients, such as symptoms, functioning and quality of life. Read more about the critical role PRO data play in the clinical and research settings and why your voice matters!
Wednesday, March 28th, marks the first Progressive MS Day, an annual day of awareness that calls for more research to improve our understanding of MS progression, help advance care and reduce disability. Learn more about this important day and ways you can participate. This Progressive MS Day we’d like to introduce you to a woman living with progressive MS whose positive attitude and outgoing personality have a remarkable impact – Karen Jackson.

Our Repository Spotlight features ACP’s recently announced collaboration with Regeneron Genetics Center that will sequence the entire exome region of all DNA samples in the ACP Repository.

Our iConquerMS Spotlight highlights data presented by Dr. Robert McBurney at the 2018 ACTRIMS forum which summarize and compare the characteristics of participants in the iConquerMS network with relapsing remitting and progressive forms of MS.

March is Multiple Sclerosis Awareness month. The National MS Society organizes events all over the country to raise awareness about MS and help those struggling with it. Do you have activities planned for MS Awareness month to support the cause? Are there activities that you’d like to see ACP undertake? Feel free to email us your ideas or plans (and include a picture from your event!). We’d love to hear from you. We love to incorporate input from our readers into our planning. If you haven’t already done so, please complete our brief 12-question survey and share your thoughts on future newsletters, important areas of research, etc. We appreciate your feedback.

We hope you enjoy our newsletter and encourage you to share it with anyone you think may be interested in learning more about ACP. With spring upon us, we wait for the snow to melt in anticipation of new growth and blooming flowers. By the same token, we look forward to working toward new growth of our collaborations and programs to accelerate MS research toward groundbreaking discoveries.

The Accelerated Cure Project Team
RealTalkMS – “News, Views, Interviews and Breakthroughs”

RealTalkMS is a weekly podcast well worth listening to for anyone who is affected by MS. Hosted by Jon Strum, it provides a platform to stay up-to-date on the latest information about multiple sclerosis. Jon packs a wealth of information into each 30-minute podcast. He covers a wide range of topics, from groundbreaking MS research to legislation surrounding healthcare issues. RealTalkMS also features interviews with neuroscientists, MS activists, MS caregivers and others who work to improve the quality of life for those living with MS. Two recent guests on the podcast were Dr. Robert McBurney and David Gwynne of the Accelerated Cure Project. In this episode, Robert and David talk about some of ACP’s major initiatives and ways that you can be a part of MS research. In addition, the RealTalkMS website features a list of helpful MS resources for those living with MS. According to Jon, “My goal is simple – to keep our conversation going until there’s no longer a need to talk about multiple sclerosis, except in the past tense.”

Since its inception 6 months ago, RealTalkMS has gained an audience of over 2,000 listeners. Jon’s podcasts are intended to benefit people with MS, their caregivers, family members and friends, but everyone will find interesting content when they tune in. According to Jon, “I started the podcast in the beginning of October and I was hopeful that somebody would want to listen to it. I’m amazed at how fast it’s growing. I think it helps everybody understand at least a part of the MS journey a little bit better.”

Jon and his family have had a difficult journey with MS. His wife was diagnosed with secondary progressive MS in 1997. Prior to her diagnosis, she was an avid cyclist, riding her bike 40 miles every day. Within a few short years, she became a quadriplegic, no longer having the use of her arms or legs. Her MS has continued to progress, affecting her vision, cognitive abilities, her ability to swallow and even speak. In Jon’s words, “What we’ve gone through has been incredibly difficult. I try to be involved because my hope is that maybe through the work that I and a zillion other people out there try to do every day, maybe one less family will go through what we did.”
Jon has his finger on the pulse of MS research through his role as a lay member of the Scientific Steering Committee of the International Progressive MS Alliance, a growing global initiative to end progressive MS. The Alliance, founded by a number of international MS organizations, awarded $15 million dollars in research grants in the last year to support promising MS research around the world. This level of international participation and collaboration is unprecedented and holds great promise for groundbreaking discoveries.

The Scientific Steering Committee oversees the peer review process of projects and recommends projects for funding. Jon states, “Through my participation in the Progressive MS Alliance, I’m able to hear firsthand some of the amazing research going on right now. The lay members of the committee are there to represent the interest of families that are living with progressive MS and to make sure that, when we’re talking about science and research, it has a really constructive application at the end of the day… Part of the reason I started the podcast is that I’m hearing about all of the amazing science going on, information that makes me personally hopeful, and I want to share that. I thought if I could break this information down into easily understood language, a podcast might help other people living with MS feel as hopeful as I do.”

Jon is an active member of the National MS Society’s MS Activist Network. As such, he has discussed healthcare issues that are of prime importance to the MS community with legislators and advocated for change. Earlier this month, at the Public Policy Conference in Washington, D.C., Jon spoke with elected officials from California about things like access to affordable medication and transparency in prescription medication pricing. In Jon’s words, “… if not life and death, and sometimes they are, these are certainly quality of life issues that are profound.” Jon’s deep involvement in MS advocacy was part of his inspiration to launch RealTalkMS. According to Jon, “When living with MS so many of the things that happen to you are out of your control, but deciding that you’re going to advocate on behalf of yourself and your own self interests – that’s 100% within your control. And, when you exercise that power, it feels great. We use the podcast to not only provide information, but also to make listeners aware they can play an active role in advocating on their own behalf. Personally, I find that incredibly empowering. So, I would think that others would be equally empowered.”
When asked what he enjoys most about his podcast, Jon states, “There’s not a part I don’t love. It’s provided me with a wonderful opportunity to meet some of the people who are leading the charge when it comes to research or activism or legislation or whatever we happen to be talking about that week. It’s put me in touch with the individuals who are the heroes of the story. I also enjoy the emails that I receive from people who seem to like what I’m doing or want to let me know that a particular episode meant something to them.”

Each year, the month of March is a time to raise awareness about multiple sclerosis, to educate more people about what life with MS can be like, and to help those that suffer from it. RealTalkMS is packed with information and inspiration for people living with MS. Its podcasts are interesting and easy to understand, a perfect resource to share this month and beyond.

Why we still need to talk about smoking in MS
By Farren Briggs PhD, ScM

“We already know smoking is bad, and we tell patients to stop smoking – this is not an interesting question,” wrote a grant reviewer in response to a proposal I submitted in 2009 to investigate genetic variants mediating tobacco-smoke-related MS risk. A few years earlier I may have agreed – but in the interim I realized the opportunities to study smoking in MS. In response to the reviewer, I wrote “Yes, I do agree that we know smoking increases the risk for MS, however, we do not know how. Tobacco smoke is one of a few environmental factors influencing the risk for MS, and therefore if we can identify the mechanisms through which smoking is bad then we might uncover novel targets for drug development.” The grant was funded, and it is an argument I still champion. Today, it is still unclear how smoking influences risk. The simplest explanation is that it is a pro-inflammatory agent. It is now generally accepted that smoking also accelerates the progression of MS – though studies investigating progression have varied in their findings for two reasons: the measure of progression used (e.g. relapse activity, walking speed, comorbidity burden, etc.) and how smoking was measured (ever versus never smoker, current versus never non-smoker, average number of packs smoked per day, etc.).
Nonetheless, there is a valid reason to continue supporting research investigating the impact of tobacco smoke on MS as demonstrated by two studies from last month.

*Multiple Sclerosis Journal* published a German study of 263 persons with MS (PwMS) who were untreated and recently diagnosed with relapsing-remitting MS or clinically isolated syndrome. The researchers’ goal was to identify factors contributing to very early brain volume loss in the study participants. In recent years it has become apparent that there is brain volume loss in those with MS, and this occurs very early in some individuals – therefore it is an active area of research. In this study, data on smoking and body mass index (BMI) was collected. Then two genetic variants were genotyped from blood samples — *HLA-DRB1*15:01 (the strongest MS genetic risk factor) and *APOE* ε4 (the strongest Alzheimer’s disease genetic risk factor). MRIs were performed on all participants to calculate brain volume and other related measures. BMI and the genetic variants were not associated with brain volume. However, current smokers had greater atrophy in total brain volume (specifically in gray matter) than non-smokers. The smoking result is consistent with a few other studies in non-MS populations. But why does smoking impact brain volume, and why the gray but not white matter? Is it because nicotine increases the permeability of the blood-brain-barrier that sequesters our brains from the rest of our bodies? Is it an increase in oxidative stress in the brain? Would e-cigarettes have the same impact? This study is intriguing, particularly considering these are very early in MS, and the lack of association of brain volume with BMI and genetic variants.

The second study, published in *Neurology*, was a Danish study of 834 relapsing remitting PwMS who were all treated with interferon beta (IFN-β). The study participants completed a survey on their smoking habits at baseline; there was also genetic data for *HLA-DRB1*15:01 and two other variants of interest. Study participants underwent a neurologic examination at baseline and then every three months for one year. As part of each neurologic examination, a physician would ask the participant to report the number of relapses occurring since the last clinical visit. Well, none of the genetic variants were associated with relapse activity. Unfortunately, smokers had a 20% increase in relapse activity than non-smokers, and the more a PwMS smoked, the greater the relapse activity. Remember, all these individuals were on IFN-β therapy, which is supposed to reduce the number of relapses. Thus, the authors concluded that smoking reduced the effectiveness of IFN-β for treating relapses in PwMS. I personally think this is a big deal – but of course, these findings need to be replicated. Nonetheless, erring on the side of caution, these findings suggest promoting smoking cessation for those who are active smokers.
Back in November, I published a paper on a study of 950 PwMS. My findings showed active smokers had worse physical and mental quality of life, and greater overall disability than non-smokers. The results did surprise me, as smoking negatively affected all measures we looked at in the paper. So, okay, we know smoking is bad, really bad… but why do some continue to smoke? Is it their coping strategy? Is it a lack of health promotion by healthcare professionals? Is it a lack of smoking cessation resources? Maybe it is a little bit of everything, we all have a part in continuing this conversation. I will continue to study the role of smoking in MS. I want to get at the how and why, and strengthen the argument for MS-tailored smoking cessation programs.


The Patient Perspective Makes a Big Difference

At some point, most people rely on their physician’s recommendations and treatment for health maintenance or when they are sick. Doctors, in turn, rely on changes in health status (otherwise known as health outcomes) to determine a course of treatment, whether preventive or remedial. Health outcomes are classified according to the source from which they are collected. A physician reported outcome is one collected by a physician in the course of clinical care (for example, the physical exam, imaging scans or lab tests). A patient reported outcome (PRO) is one directly reported by the patient who experienced it. PROs are most often factors that matter most to the patient, such as symptoms, functioning and quality of life. Although physician reported outcomes are useful in assessing disease activity and severity, they do not help clinicians fully understand the true impact of illness on patients. For example, multiple sclerosis affects a wide variety of things, including employment status, social and family relationships, sexual satisfaction, pain, fatigue, enjoyment of life, vision, bladder and bowel control, cognition, as well as emotional well-being. These profound effects on patients' quality of life (which can influence the patient’s adherence to treatment) are often not captured by the physician as a part of routine clinical care. PRO and physician reported outcomes measure different components of a patient’s well-being and should ideally be used together to assess a patient’s health status and to provide individualized treatment.
PRO data can help physicians identify minimal changes in disease activity which may otherwise go unnoticed, thus improving their assessment of symptoms and enabling them to provide better quality of care and encourage adherence to treatment plans. This is information that might otherwise be lost in brief check-ups or in a patient’s inability to communicate aspects of their condition as they progress through the course of illness. In addition, consideration of PRO data in the course of clinical care can foster stronger physician-patient relationships, encourage patients to increase ownership in managing their disease, and help physicians address patient concerns directly. In research, PROs provide useful information whenever the patient perspective enters the equation. For example, PROs are used in clinical trials to measure the risk and benefit of new drugs and therapies, and also play a significant role in determining when a study ends. Once a medication is FDA-approved PROs become an important tool to guide patients and clinicians to make the best treatment decisions possible.

PROs measure one or more specific aspect(s) of the patient experience from their perspective. These aspects are called “constructs”. The most commonly used PRO questionnaires focus on what is commonly referred to as health-related quality of life, which are the aspects of quality of life that are related to health. This includes symptoms, functioning, emotional well-being, satisfaction with care/treatment, as well as knowledge of or adherence to therapy. PRO data can be collected in a variety of ways, for example through questionnaires, patient logs, or patient interviews. These methods of collection are referred to as “instruments”, “measures”, “scales” or “tools”. Regardless of the method, data should be provided directly by the patient whenever possible. Questionnaires that measure a single construct are referred to as “unidimensional”, and those that address multiple constructs are “multi-dimensional”. Questionnaires can be paper-based or electronic (administered via computer, tablet or smartphone). All have standardized scoring which provides consistent measure of the patient’s health status. Of note, PRO data collected from an interview can only be considered “patient reported” if the interviewer recording the patient responses is not confounding the data in any way by adding their own observations or opinions.
Typically, PRO instruments must undergo extensive validation and testing before they are used. They can be generic (designed to apply to a wide variety of patient groups) or disease-specific (developed specifically to assess the impact of a particular disease). The **SF-36** is an example of a generic questionnaire that many MS patients may recognize. The **Multiple Sclerosis Quality of Life Inventory (MSQLI)** consists of 10 individual scales, providing both generic and MS-specific quality of life measures.

With the exception of conditions that rely on patients’ reports (such as depression), PRO data is not widely used in the clinical setting. Despite the potential for broad benefit, clinicians’ main concerns are that additional data collection would be burdensome. PRO questionnaires may add costs that some providers may find difficult to absorb. Interestingly, some feel that PROs are not necessary given they have already established a good relationship with their patients. In this case, clinicians believe their assessment of the treatment benefits is consistent with the patient’s experience, which may not always be the case. PRO data also have some inherent limitations. It can be difficult to collect. Sometimes patients don’t fully complete instruments, leading to missing data (if it cannot be obtained on follow-up). Surveys rely on patient recall, which may result in inaccurate information. In addition, patient responses may vary depending on cultural, ethnic, language, or educational differences among respondents. However, even with these limitations in mind, PROs provide essential input in both the clinical and research settings.

The **Patient-Centered Outcomes Research Institute (PCORI)** is an independent, nonprofit organization in Washington, D.C. that provides funding for comparative **clinical effectiveness research** and works to influence clinical and healthcare research funded by others to be more patient-centered. PROs are the core of their mission. PCORI was founded on the premise that patients, their families, and clinicians should have reliable information to decide which treatment or other care option is best for them. One of their primary goals is to increase the amount and quality of PRO data available to support health decisions.
As discussed on our June 2017 newsletter, iConquerMS™ is a Patient Powered Research Network, funded in part by PCORI, developed to advance and accelerate patient-centered research in MS. Its participants complete surveys on a number of topics through a secure portal, including demographics, MS symptoms and MS-specific PRO instruments (the PROMIS® Global Health Survey, and the Neuro-QoL Adult Short Forms).

iConquerMS enables all people living with MS to participate in research by providing their data, while effectively removing the main barrier that prevents the use of PRO data in MS research by making it readily available to investigators (either by providing access to the existing database of information, or by collecting new data from iConquerMS members). This collaboration between people affected by MS and the research community is part of an effort to transform MS research, improve the quality of care for MS patients and may one day play a significant role in finding a cure. If you haven’t already done so, please consider joining the iConquerMS community today and add your voice to the thousands already driving research forward!
First Progressive MS Day Recognized Across the United States

The Accelerated Cure Project is pleased to participate in the first Progressive MS Day, being observed on March 28, 2018. In partnership with the multiple sclerosis (MS) community and a number of state governments across the country, Progressive MS Day shows support, offers education, and calls for more research to advance care and reduce disability for those living with the most debilitating forms of the disease.

Wondering how you can participate? The MS community is invited to join the conversation on Facebook, Twitter, Instagram and LinkedIn using the official hashtag: #ProgressiveMSDay. All are invited to highlight resources, programs and services for those living with progressive forms of MS, as well as share their stories of perseverance and hope. Visit [Gene.com](http://Gene.com) to learn more about featured patients. In addition, show your support with a custom [Facebook profile frame](#) for the day.

Progressive forms of MS are characterized by a sustained build-up of symptoms with an insidious increase in disability.\(^1\) With Primary Progressive MS (PPMS) in particular, disability accumulates twice as fast as in those with Relapsing Remitting MS (RRMS). This means that people with PPMS experience more problems with walking, more difficulty remaining in the workforce, and require more assistance with everyday activities.\(^2\) Approximately 400,000 people in the U.S are living with MS.\(^3\) Up to 15 percent are diagnosed with PPMS, and the majority of those diagnosed with RRMS will transition to a progressive form later in life.\(^4\)

Progressive forms of MS remain frustratingly difficult to treat, due to a history of unsuccessful clinical trials and limited understanding of why progression occurs. While more than a dozen [medicines for RRMS](#) have been approved since the 1990s, there is one FDA-approved [treatment for PPMS](#). More research and a deeper understanding of the biology driving this condition are needed.
Groups recognizing Progressive MS Day include Genentech, as well as several national MS patient advocacy organizations and MS centers. Governments around the country will also join together to formally proclaim March 28th as Progressive MS Day; these states include California, Georgia, Michigan and Colorado.


Karen’s Silver Lining

Wednesday, March 28th, marks the first Progressive MS Day, an annual day of awareness that calls for more research to improve our understanding of MS progression, help advance care and reduce disability. It’s also a day to recognize and bring attention to people who live with progressive MS. This Progressive MS Day we’d like introduce you to a woman whose positive attitude and outgoing personality have a remarkable impact – Karen Jackson.
Karen lives in the Washington, D.C. area. She graduated from the University of Maryland with a bachelor’s degree in kinesiology and worked as a certified athletic trainer for fifteen years. She was diagnosed with relapsing remitting MS when she was 36, in the prime of her life and career. She started noticing problems with her gait, balance and mobility two years before her diagnosis. Because of her training and experience, she had an inside track on exploring possible reasons for her symptoms. After her diagnosis of primary progressive MS (PPMS) in 2003, Karen transitioned to an administrative position in an orthopedic practice. In Karen’s words, “At the end of the day my journey with MS was relatively without speed bumps because I didn’t have to hide my diagnosis. Everyone I was working for was supportive and I just continued on the journey. When it became more dangerous for me to take care of the kids (athletes) on the fields as a trainer I was able to transfer those skills and go into an administrative position… Learning new things on the administrative side opened another door and it allowed me to keep working.” Karen has enjoyed retirement for the last two years and is now busier than she has ever been.

Karen tried all of the disease-modifying therapies that were available in the 1990’s (Avonex, Novantrone and Copaxone), but none were helpful. Over the course of the first ten years living with MS, her symptoms slowly progressed to the point that she used a cane to walk, and relied on a scooter to travel longer distances. In 2003, she traveled to Northwestern University hospital in Chicago to enroll in a clinical trial. It was a stem cell transplant study that carried a significant amount of risk. Despite this, Karen had no hesitation about participating. “There was nothing else out there for me. I was willing to take the risk to help better understand and treat MS.” In the end, Karen did not qualify for the study because of her advanced symptoms, and she was given the diagnosis of PPMS for the first time. According to Karen, “I now know that I was probably PPMS from the start. It manifested so slowly, no doctor would ‘label’ me as PPMS right away.” When asked how she felt about her change in diagnosis, she said, “I was angry because it was still back in that time when they said, ‘there’s nothing we can do to help you, so just go home and hang out.’” Reflecting back on this series of events, Karen looks on the bright side, “At the end of the day, it all worked out because the neurologist that was part of that study knew someone at Johns Hopkins who was doing some research that might offer me options. I met with the Hopkins neurologist and he connected me to clinical trials for PPMS.” This same neurologist has been Karen’s MS care provider for the last 15 years. In Karen’s words, “He’s had a significant impact on my life with MS and is always supportive and open to dialogue to discuss treatment options. He keeps me in the pipeline in case something new comes along.”

Karen participated in a clinical trial with Rituximab in 2006 and is taking it today. She is currently participating in five different clinical studies at NIH and Johns Hopkins. According to Karen, “Participating in research is a personal decision. Some people feel like they are guinea pigs when they participate in clinical trials. For me, it’s incredibly important. It’s advancing research. It’s advancing us toward the answer and it allows me to participate.”
Karen has also participated in a number of alternative treatments for her MS over the years, including yoga, aquatic therapy, acupuncture and, most recently, occupational therapy.

Karen has experienced a slow progression of MS symptoms, which mostly involve difficulties with coordination and clumsiness. She now uses a wheelchair to ambulate. She states, “right now my fine motor skills on the right side are a challenge. I am right hand dominant. The beauty of it is that my brain is starting to train my left side, so my left side is doing much more than it ever has. I don’t have the fine motor control, but you figure it out. Things change and you adjust. A lot of folks are a lot worse off than me. Everyone has challenges in life. It’s how you choose to accept them and deal with them. That’s the difference.”

When asked how MS currently affects her life, “I’ve lost the ability to be spontaneous. Yes, everybody has to plan their days, but I have to plan every day, every minute, every second, every everything. That’s the biggest frustration, and it’s exhausting.”

When asked how she best copes with progressive MS, Karen says, “I try to keep a positive attitude and always look for the silver lining. You have a choice in life. Don’t we all? I can choose to be miserable. I can do the pity party. I can do it with the best of them, but it’s not going to do anything for me and people don’t want to be around you if you’re going to be that way. I have an incredible support system that’s just amazing. I am incredibly blessed … I have my moments, I have my days just like anybody else in any other challenge, but you figure it out like everything else.”

Karen is deeply passionate about MS advocacy and policy. She’s been an active volunteer for the Greater DC-Maryland Chapter of the National MS Society (NMSS), since she was diagnosed with MS in 1996. Volunteering is an activity that helps her maintain her independence. She speaks publicly to increase awareness of MS and will talk to anybody who approaches her. She was awarded the National Capital’s MS Ambassador of the Year Award in 2007, and was inducted into the Society’s Advocacy Hall of Fame in 2011. Karen recently told her story at a briefing on Capitol Hill for members of Congress and their staff, asking Congress to continue providing funding for MS research. According to Karen, “I became the ‘face’ of PPMS to remind Congress that what is decided on Capitol Hill has a direct effect on real people. I am not anonymous. I am not just a number.” When asked what advocacy means to her, Karen says, “It means I’m participating. It means that I have a say in my care. I cannot just sit back. I’m raising awareness. My voice is there and I’m visible. I’m visible because of the optics when I roll into the room. I’m in a chair and they don’t expect me to be able to
Karen also participates in iConquerMS™, and is a member of the Engagement Committee for the Network. This committee is responsible for raising awareness about iConquerMS. The ability to help drive research by sharing her information and connecting with researchers through iConquerMS is inspiring for Karen. In her words, “Understanding the iConquerMS philosophy that data is power gives me power. It’s letting me know that my data is important.” Karen also states, “We’re now getting transparency with iConquerMS. We want to know the results of studies, and for a long time we didn’t know them. That was kind of a secret, if you will. We’re also getting collaboration with iConquerMS, which is really important. We’ve finally gotten to the point now where researchers realize they should collaborate so they can pull it all together down the road … iConquerMS is going to expand studies. It’s not two or three hundred people’s worth of data that we can use to advance the mission (which we thought was huge). We now have 4,500 records and can offer a gateway to that data if a researcher submits a proposal… And we control it. It’s us, folks with MS, that have a say and that is significant.”

Karen’s ability to find a silver lining and her “can do” attitude are inspirational and infectious. She meets the challenges of every day life with gratitude and perseverance. She’s a firm believer in the value of research to better understand and treat MS. She works tirelessly to advocate for those living with MS and effect change on policies that influence their care and quality of life. We appreciate her sharing her MS journey and perspective for the benefit of others in the MS community.

**Repository Spotlight – Regeneron Genetics Center**

Regeneron Genetics Center is a division of Regeneron Pharmaceuticals, Inc. The Accelerated Cure Project recently announced a collaboration with Regeneron Genetics Center that will sequence the entire exome region of the more than 3,200 DNA samples in the ACP Repository. The exome is the protein-coding region of the human genome, which contains most of the known inherited gene differences associated with all diseases. These data will be returned the ACP Repository database and made available for further research. "This collaboration will enhance our understanding of the MS genome," said Robert McBurney. "Whole exome sequencing will add valuable new information to the genome-wide 'risk gene' dataset that has already been generated from the DNA samples in the ACP Repository by the International MS Genetics Consortium (IMSGC). Combining this new genetic information with the extensive phenotypic information collected for each sample donor will undoubtedly lead to new insights into the causes and mechanisms of multiple sclerosis."
iConquerMS Spotlight – ACTRIMS Forum 2018

The ACTRIMS Forum 2018 took place February 1-3 in San Diego, at which some of the leading minds in MS research discussed exciting new findings. Dr. Robert McBurney presented data at this meeting summarizing and comparing the characteristics of participants in the iConquerMS network with relapsing remitting and those with progressive forms of MS. These data revealed interesting differences in the ranking of symptoms, functioning and quality of life across the different forms of MS. For instance, lower extremity functional disability was more common in people with progressive MS and fatigue was a common symptom across the board. This summary of the iConquerMS network highlights areas of quality of life that affect people with relapsing and progressive forms of MS and provides an excellent resource for future research.

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