Dear Friends,

According to the Ethiopian Proverb, “When spider webs unite, they can tie up a lion.” While some may debate whether or not that’s actually true, the analogy holds. MS is a chronic, often disabling, disease that attacks the central nervous system. Much like a lion is a hunter in the jungle, MS often feels like a predator in the lives of those living with it. There are a number of organizations working to improve the lives of those living with MS and hasten research toward its cure. Reflecting back, 2018 has been a year full of powerful collaborations for ACP. Working together we look forward to “spinning a stronger web” to stop MS and the destruction it causes. Our first article covers how we are uniting with our allies to make a bigger impact in the fight against MS worldwide.

The ACP newsletter is one of the vehicles through which we keep you informed about MS related topics, new findings in MS research, the latest news from ACP, and our volunteers’ contributions. Each issue in 2018 has been focused on a theme we hope our readers have found interesting and helpful. We’ve covered a wealth of information over the last 12 months. For those who would like to revisit any of these subjects, they are just a click away!

The iConquerMS initiative is truly unique in that it is governed by a majority of people with MS. The Governing Board, Engagement and Research committees all have a pivotal role in the success of the initiative. In September, we gathered the members of the iConquerMS governance, along with other stakeholders in MS, at our annual Leadership Summit to envision the future of iConquerMS and the impact it can have on the lives, health, and wellbeing of people affected by MS. The focus of this year’s meeting was transformational collaborations. Having formed or strengthened many key partnerships in 2018, we look forward to an exciting and productive New Year! Read more about the powerful possibilities in ACP’s future and how they could impact you!
Research on the genetics of autoimmune diseases is key to understanding disease processes, as well as identifying targets for new drugs. Our Repository Spotlight features studies done in the past year using the ACP Repository as a resource to advance and accelerate cutting edge research.

People living with MS are the heart and soul of iConquerMS. A primary objective of the initiative is to enable all people living with MS to participate in research. Ideally, tens of thousands of people from all parts of the country, from all backgrounds and ethnic groups, and of all ages and stages of living with MS will participate. This diversity will create a rich, interactive resource for MS research. Our iConquerMS Spotlight covers the significant progress we’ve made in the past year toward realizing this vision.

With the season of giving upon us, we would like to express our heartfelt thanks for the many ways that our partners, donors, and volunteers have given of their time, talents and resources. Your contributions make a significant difference in ACP’s success. We hope you enjoy our newsletter and encourage you to share it with anyone you think may be interested in learning more about ACP. We wish you and your family a happy holiday season and wonderful New Year.

The Accelerated Cure Project Team

**Teamwork Makes the Dream Work**

The Accelerated Cure Project (ACP) is a small organization, comprised of 6 hard working individuals, making a big impact toward curing MS worldwide. 2018 has been a year full of productive collaborations. We’ve made significant strides in our mission, thanks to a cooperative effort with our partners.

- **Many of our readers have participated in the ACP Repository. Wondering how we manage all of the data we’re collecting?** ACP Repository samples continue to advance MS research around the globe. Every sample is associated with a rich set of data, both patient and clinician reported. Researchers using samples are returning their results to the Repository database for sharing with other researchers. ACP will be using BC Platforms’ data management system and global network to manage and grow the Repository. This represents a major step toward realizing the vision for the ACP Repository as a catalyst for a cure.

- **Ever wish you had more of a say in research and drug development?** ACP and EMD Serono have entered into a first-of-its kind partnership to ensure patients’ complete experience with MS is captured and considered in the drug development process. This is an unprecedented opportunity for the collective voices and insights of people with MS to be heard and to drive real progress in research, drug development, and ultimately in the fight against MS.

- **Are you curious how the fight against MS is being globalized?** More and more, clinicians and researchers are collecting feedback from patients on their symptoms and functioning to determine what symptoms and quality-of-life impacts are most important to them. Many different questionnaires are currently being used across the globe to collect this important information. ACP is working with the Italian MS Society to standardize these surveys so they can be translated and used to improve healthcare and quality of life for people with MS worldwide.
The ACP Repository's purpose is to be an easily accessible source of samples and associated data for the research community. Scientists and clinicians who use these samples must agree to return their research results back to the Repository database for sharing with other researchers. At present, the database contains a diverse collection of information collected from Repository participants, as well as genomic and other research data generated by scientists. Ideally this wealth of knowledge could be analyzed in its entirety, enabling the ACP Repository to be a rich “open source” resource that can be mined by researchers. BC Platforms is a world leader in providing genomic data management and analysis solutions for large-scale collaborative research projects. Their expertise lies in integrating phenotype data (such as data collected from ACP Repository subjects) with genetic data. Their data management platform is HIPAA compliant and offers flexibility, as well as data security. BC Platforms has also established a global network, BCRQUEST.COM, which combines the datasets of biobanks around the world. ACP will be using BC Platforms’ data management system and BCRQUEST.COM to manage and grow its Repository. All collected and returned data will be integrated into one easily accessible data management system. The BC Platforms data management system will also allow ACP to streamline the process of selecting samples based on investigators’ specific research requirements. Being able to service more requests for Repository samples means more studies can be done -- accelerating the research needed for better treatments, diagnoses, and cures. This represents a major step toward realizing the vision for the ACP Repository, and will further facilitate collaboration between ACP and researchers.

EMD Serono researchers strive to improve the lives of people living with MS by offering better therapies and support services, made possible by cutting edge research. Until now, input from people living with MS hasn’t been routinely considered in the drug development process throughout the industry. The U.S. Food and Drug Administration (FDA) recently released guidance related to Patient-Focused Drug Development (PFDD). These documents outline a systematic approach to ensure patients' experiences, perspectives, needs, and priorities are captured and meaningfully incorporated into drug development and evaluation. ACP and EMD Serono have entered into a groundbreaking collaboration that is well aligned with
This collaboration between iConquerMS and EMD Serono, the first of its kind in MS research, is an important opportunity for the collective voices and insights of people with MS to be heard and to drive real progress in research, drug development, and in the fight against MS.

ACP is working with individuals and organizations worldwide to advance MS research. One such organization is the Italian MS Society. There are many MS treatment options. Each carries a different level of therapeutic benefit and risk. Unfortunately, there isn’t enough information available about the effects of various treatments on the symptoms, disabilities and quality of life of people with MS. This makes it difficult for people with MS and their physicians to make therapeutic choices. Patient reported outcomes (PROs) are designed to collect important information for treatment selection and other aspects of living with MS. At present, there are a very large number of surveys designed to collect PRO data, with little standardization or harmonization. Researchers need to determine how these varied data can be translated and used to improve healthcare and quality of life for people with MS. To address this issue, ACP and the Italian MS Society (both focused on collecting PRO data) are working together to standardize and unify PRO measures across cultures. This collaboration aims to establish a system and tools for collecting, presenting and interpreting PRO data for use in research and in shared healthcare decision-making so everyone involved can speak the same language. The end result will bring outcomes that matter most to people affected by MS into research and ultimately, every aspect of their care.

RealTalk MS is a successful podcast series (established by Jon Strum), which currently reaches an audience of over 4,500 listeners. Weekly episodes offer a wealth of information and encouragement to people affected by MS. With the joint goal of promoting and communicating research results and activities to the MS community, ACP and Jon Strum will work together to increase the reach and visibility of both RealTalk MS and iConquerMS. This partnership holds great promise for both programs. The increased visibility through Jon’s podcasts has the potential to boost iConquerMS enrollment, and enables more effective communication of iConquerMS research activities and results to the MS community. RealTalk MS, in turn, will receive input on podcast topics of interest from the iConquerMS community, as well as connections to potential interviewees who are doing important and interesting work in MS. In addition, both teams will work together to seek funding to support these activities, which increases their sustainability.
ACP recently announced a powerful collaboration with the National MS Society (the Society) to facilitate their common goal, a world free of MS. The two organizations will work together to speed the pace of research for better treatments and a cure for MS. Through this collaboration, the Society will partner with ACP to leverage the iConquerMS network to drive engagement of people with MS in the design, conduct and impact of MS research, as well as increase input and involvement from clinicians, researchers, and others affected by MS. Through this collaboration, the Society will have access to the iConquerMS platform, data, and participant input for its research activities, such as policy surveys, quality of life questionnaires, data analyses, and other activities conducted by the Society to support its goal of delivering breakthroughs to a cure. The Society will provide financial and in-kind support for the initiative, including promoting and recruiting for iConquerMS research opportunities and sharing questions and topics for research among Society support groups and membership. ACP will continue its efforts to increase enrollment in the iConquerMS network, and contribute this platform to enable people with MS to live their best lives, and advance cures for MS. The collaboration between the Society and ACP holds great potential for speeding progress toward better MS treatments and, ultimately, a cure.

Since its inception, collaboration has been central to ACP’s mission. In COO, Sara Loud’s words, “To me, the collaborative nature of our work is most exciting… A complex disease like MS is unlikely to be cured in a fragmented research environment. The ACP Repository is really such a brilliant (and definitely novel) approach to fostering collaboration by requiring researchers to return their research results back to us so that we can share them with other researchers… We’ve taken this collaboration a giant step further through iConquerMS by bringing the most important experts on MS, the people affected by the disease, front and center into research. The ‘people-power’ of iConquerMS means that people affected by the disease are driving, shaping, and contributing to MS research in brand new ways — ways that will ensure that research gets done on topics that matter most to them.”
A Look Back – Newsletter Highlights

The ACP newsletter is one of the vehicles through which we keep you informed about MS related topics, new findings in MS research, the latest news from ACP, and our volunteers’ contributions. We’ve covered a wealth of information over the last 12 months. As the year draws to a close, we’d like to review some of our newsletter themes from 2018. For those who would like to revisit any of them, they are just a click away!

- **MS caregivers are a priceless gift.** Their [support and care](#) enable those living with MS to live the fullest life possible. Their unique perspective as the closest and most constant observer of the person living with MS has the potential to [transform](#) the research process. Providing round the clock care can be exhausting. In our February and November issues, we explored some [resources](#) that can help make this important job easier.

- **The only way MS research will benefit all is if a diversity of people participate.** The MS Minority Research Engagement Partnership Network is working hard to understand the barriers to [minority participation in research](#) and to overcome them. Read more about the work the Network is doing to help solve this problem.

- **How can clinicians and researchers fully understand the true impact of MS?** By collecting information directly from those who live with the disease! There is growing awareness of the importance of [Patient Reported Outcomes](#) in healthcare decision-making and for collecting comprehensive data for research. iConquerMS is on the pulse of this new trend, ensuring the voice of the MS community is heard!

- **Is stem cell therapy the MS treatment of the future?** [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.

- **Do you ever wonder why MS affects men and women differently?** There is mounting evidence that [testosterone](#), [estrogen](#) and [progesterone](#) affect not only the reproductive system, but also impact the nervous and immune systems.

- **Are you curious if the risk of developing MS can be influenced?** It is generally agreed that a variety of [factors](#) contribute to an individual developing MS. Some are genetic and therefore inherited, while others are environmental and can be controlled.

- **Have you considered trying cannabis to relieve your MS symptoms?** Research shows [marijuana](#) is effective in relieving spasticity, spasms, sleep, and in some cases, pain. However, there is still much controversy surrounding this alternative treatment.

- **Interested in what’s happening in MS research?** Dr. Farren Briggs’ articles provide our readers with relevant information on [trending topics](#) in MS research.
Caregiving is challenging work in many respects, physically, emotionally and financially. Providing care to a person with MS requires the person with the disease and the person providing support to be a team, working together. In February we featured care partnerships, as well as some valuable resources that are available for both members of this important relationship. We also covered how assistance dogs can help with the completion of daily tasks and emotional support.

Caregiving is exhausting work, causing some to burn themselves out. In November, we explored the topic of caregiver burden, and ways to help make this important job easier. Caregivers, in general, have a lot to offer toward advancing clinical research. Their knowledge of side effects, as well as physical or cognitive changes, and how these affect functioning and quality of life is relevant and vitally important to consider at every step of the research process. Caring for a loved one with a long-term illness is a 24/7 job that can span decades. Those providing support are often so focused on their partner’s needs they may not have time, or think to take care of their own. Families living with chronic disease cannot afford to have both the patient and caregiver sick at the same time. It’s imperative for researchers to study caregiver health and burden, as well as coping mechanisms and strategies. In November, we stressed the importance of caregiver inclusion in research, as well as caregiver-focused research.

It’s a known fact that people of different races and ethnicities can have varied responses to the same medicine. Diversity in clinical trials is key to ensuring that new discoveries and treatments are relevant to everyone. Less than 10 percent of subjects enrolled in clinical trials today are minorities. In an effort to understand why this disparity exists, the MS Minority Research Engagement Partnership Network conducted a survey asking about people’s attitudes and concerns about research and other related topics. In February we brought you their interesting results, and the work the Network is doing to ensure that MS research benefits all people.

Clinicians and researchers need an accurate assessment of an individual’s health (or changes in their health) in order to determine a course of treatment or the direction of a research study. This information can be collected by a physician, or directly from a patient (or subject). Patient reported outcomes (PROs) help clinicians understand the true impact of illness on patients, as they are reported from the person experiencing it. In research, PROs are used to help investigators identify trends and patterns that would not be visible otherwise and use these insights to answer key questions. In March we explored how these important data are collected and how your experience and perspective can make a pivotal difference.

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. 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. In April, we featured these pioneering treatments, their potential benefits, and limitations. Also highlighted in April are the experience and perspective of two individuals, both of whom received stem
cell therapy for their MS and are working to spread the message of hope to others living with MS, Richard Cohen and David Bexfield.

There are many gender differences in MS. In May we covered MS and women, including the relationship between MS and the menstrual cycle and menopause, as well as pregnancy and breastfeeding. Also included were results published in the Women and MS report, which reveal many of the challenges women living with MS face in their personal and professional lives. In June we focused on MS in men, including the role testosterone plays in MS and the powerful possibilities it holds for revolutionizing MS treatments in the future, the ways MS and its treatments can impact a man’s reproductive health, as well as the challenges and emotions a man may experience in his walk with MS.

Our 2018 newsletters delved into other topics of interest for people living with MS. It is generally agreed that some people have a genetic make-up that predisposes them to MS and that one or more elements in the environment act as a trigger that leads to them developing the disease. In September, we explored some well-known and recently discovered risk factors for MS. Many people with MS are turning to alternative treatments, such as cannabis, for relief of their symptoms. Also in September, we covered what we currently know about, and the controversy surrounding this Asian herb.

MS can deeply impact the lives of those living with it. This year we brought you interviews with two remarkable individuals who maintain a “glass is half full” attitude. In January we spoke to Marc Stecker, the creator of the Wheelchair Kamikaze, an award winning blog many turn to for solace, information and humor. In March we talked to a woman living with progressive MS whose positive attitude and outgoing personality have a remarkable impact – Karen Jackson.

Dr. Farren Briggs kept us up to date on developments in MS research over the past year. His articles told us about two recent studies on movement rehabilitation and MS, which may shed light on therapies aimed at improving wellness and function in those living with the disease. Dr. Briggs also explored interesting, new information about hypertension in MS, along with the effects of diet and tobacco smoke in MS. We are grateful to Dr. Briggs for his time and expertise over the last year and look forward to reading more in 2019!

Our work is done in partnership with our volunteers. They help us with a wide variety of tasks, all of which are important to our purpose. Some of our volunteers like to assist with administrative tasks and other projects both in the office and remotely. Others give of their time and talents to host fundraising events to benefit ACP. Highlighted in June were Anna Sweeney and Frank Duffy’s boot camp event at Cressey Sports Performance, Patrick Curley’s participation in the Essex River Race, the Medeiros family annual event and scholarship, and Marion Leeds Carroll’s Music to Cure MS concert. Other 2018 fundraisers included Kemp Jaycox’s annual walk and the Mary J. Szczepanski “Never Give Up” MS Scholarship. Freda Warrington generously donates the proceeds from sales of her first book to ACP. In July, Freda published her second book, Listen to the Light: The Daughter’s A Farmer, the proceeds of which will
also benefit MS research. Donations from individuals are a vital source of funding for ACP. Those who choose to give regularly are known as our Accelerators. In July, we introduced you to one of our Accelerators, Jane. Whether our volunteers are helping with preparing mailings, fundraising, or contributing in some other way, we are grateful to each of them for their hard work and dedication on our behalf.

According to ACP’s Chief Executive Officer, Robert McBurney, ACP’s fundamental approach can be stated as “we don’t do the research, we create much-needed resources and capabilities that make MS research go faster and better.” We’re grateful for the generosity of our volunteers, who have donated countless hours to help us do this work. We’re thankful for the support of our partners and donors. We appreciate Dr. Farren Briggs keeping us abreast of new findings relating to MS in the literature. We look forward to new possibilities in the upcoming year. In Hollie Schmidt’s words (ACP’s VP of Scientific Operations), “There is always something new to learn, some new challenge to address, or some new breakthrough to celebrate. Much progress has been made in MS in the past couple of decades, and there is still much left to do. It’s exciting to be a part of it!” Stay tuned, and look for updates in future newsletters!

A Look Ahead – Transformational Collaborations

iConquerMS™ was established to enable and accelerate MS research and other initiatives with the goal of improving the health, healthcare and quality of life of people affected by MS. The initiative does this by connecting those with MS, care partners, clinicians, and researchers, and encouraging them to work together to accelerate innovation, research, and the application of new knowledge. In less than 4 years the network has grown to over 4,700 registered members, almost 3,000 of which have contributed data about themselves and their experiences of living with MS as part of REAL MS™ (Research Engagement About Life with MS). To date, iConquerMS has collaborated with researchers and organizations to enable and accelerate 11 research projects. We anticipate reaching new milestones in the New Year!

In September, the iConquerMS governance and other stakeholders in the MS community gathered at our Leadership Summit to discuss the future direction of iConquerMS. The key focus of this year’s meeting was “transformational collaborations.” One might ask, what does this type of collaboration mean? In general terms,
collaboration is defined as “the act of working with someone to produce or create something.” Taking it one step further, transformational collaboration is focused on achieving a major change in the grand scheme in which all parties are involved and uses a novel process to achieve the desired outcome. Whereas those in a traditional collaboration may have varying degrees of involvement and differing priorities, all members of a transformational collaboration are equal partners. This type of collaboration rises above individual concerns and focuses on a shared priority. The stakeholders in a transformational collaboration may initially approach the collaboration with different priorities, incentives, or approaches. These differences are a contributing factor to the transformational aspect of the relationship. These “unlikely partners” respect and recognize their differences, are willing to be flexible, and come to a shared understanding.

Representatives from many stakeholder groups attended ACP’s Leadership Summit in September (people with MS, care partners, industry, researchers and leadership from other MS organizations). Participants enjoyed stimulating dialogue throughout the meeting and agreed that patients are an underutilized hub of information in research. Participants with MS and their care partners overwhelmingly expressed they want to be heard and involved in their treatment plan. The challenge moving forward is focusing on ways to create collaborations that will transform MS research so the patient/caregiver voice is heard and prioritize benefits to people affected by MS. There is no road map for this difficult task. The iConquerMS governance and stakeholders in the MS community agreed that achieving this exciting new milestone in MS research will require approaching traditional methods from a different angle. We must bring divergent views to a common rally point and step out of our collective comfort zones.

Transformational collaborations for iConquerMS will bridge differences and reframe the research conversation and process, supporting a shared aspirational mission that forms relationships across cultures, unlocks greater value, and has more of an impact in 2019 and beyond. Summit attendees agreed that a “trusted voice” is the most impactful way of informing people about iConquerMS and encouraging them to participate. The “trusted voices” are the key influencers, such as leading MS organizations and individuals, most often in the digital space, who build communities and followers through the sharing of important and impactful information about MS. With the goal of increasing enrollment in iConquerMS, in order to more effectively impact MS research, we must increase the “trusted voices” that know about and share information about iConquerMS. With this being the key focus for 2019, iConquerMS leadership will reach out to support groups, MS organizations, and key influencers in a personalized way and relate the value of iConquerMS. Successful engagement will boost iConquerMS enrollment and build the research capacity of the network.

What might be possible if we built transformational collaborations? Those participating in this year’s conference enjoyed discussing their exciting potential from many viewpoints. From the caregiver perspective,
it was agreed treating MS should include treating the caregiver. Transformative collaborations would involve a cultural shift in which an equal emphasis is put on the health and wellbeing of the care partner, in addition to the patient. The resulting paradigm would be one in which the goal of the first neurology visit would be to understand what the care partner team needs in order to manage MS and live with it (including health assessment of the care partner).

Age perceptions and restrictions affect people living with MS. Summit attendees wondered why clinical studies have age restrictions and often limit the participation of people with MS over the age of 60. As a result, these important data are missing. The consensus was that there need to be more clinical trials involving those on the upper end of the age spectrum, to better inform treatment decisions and lifestyle and wellness choices. Transformational collaborations through iConquerMS may be one way to get these studies done and broaden the knowledge base.

As we discussed in our February 2018 newsletter, diversity and inclusion is key to ensuring medical research benefits all. Discussions at the Leadership Summit concluded information and resources could be delivered to underserved communities with the help of all MS organizations. Such efforts will increase minority enrollment in clinical trials and other research studies, including iConquerMS. Potential venues might include community centers, health fairs, libraries, or churches. The group agreed on the importance of transparency in all outreach efforts, ideally including personal stories of those living with MS.

Our current healthcare system was another hot topic of discussion at this year’s Leadership Summit. Participants talked about how transformational collaborations might revolutionize the current concept to universal healthcare -- one that is high quality, accessible and affordable for all. All recognized the importance of getting started as such a change could take decades to achieve. The group was encouraged to think about demonstration projects that might facilitate the process. The importance of getting all stakeholders on board was emphasized, as was addressing the political climate, in order to affect such a change. Transformative collaborations could also bring healthcare into the home through telemedicine in the not too distant future. Leadership Summit attendees enthusiastically discussed including a survey about healthcare delivery options (including telemedicine) through iConquerMS in the coming year.

Another interesting topic at this year’s Leadership Summit focused on nutrition and supplements. The group recognized the importance of studying the clinical outcomes of good nutrition and the beliefs surrounding it, as well as ways to provide a good diet in a different way (for example, Meals on Wheels or new meal kits). It was even suggested that a dietary component be added to clinical trials in the future. The group agreed that transformative collaborations would be instrumental in
understanding the benefit of good nutrition in people with MS, as well as provide wider access to healthy food. Input from those living with MS, sponsors, healthcare practitioners, scientists, nutritionists and dieticians would ensure the effectiveness and applicability of these efforts.

To keep the momentum going, a “Next Steps Committee” (NSC) will work together over the next year to advance the work begun at the Summit on each of these areas of transformational collaboration. The NSC has actively taken up the discussion and is making great progress building on the work of the Summit.

Collaboration has been the cornerstone of ACP’s work since its inception. In 2019 and beyond, ACP will focus on ways to create transformational collaborations for iConquerMS, ones that will transform MS research, provide value to all stakeholders, and prioritize benefits to people affected by MS. These partnerships will leverage all resources for the education and support of those affected by MS. They will evaluate existing programs and services to identify gaps, and involve those living with MS of all ages (including those outside the norm) to ensure everyone’s needs are met. We look forward to an exciting and productive New Year! Stay tuned!

Repository Spotlight – 2018 in review

Genetic research is revealing new ways for people to take action and prevent disease, as well as new ways to treat disease through personalized medicine. ACP Repository samples have played an instrumental role over the last year in studying the genetics of MS and other demyelinating diseases. In February, ACP entered into collaboration with the Regeneron Genetics Center to sequence the more than 3,200 DNA samples in the ACP
This project will shed light on the inherited gene differences associated with MS. As is the case with all studies using ACP Repository samples, these valuable results will be returned to the ACP Repository database and made available for further research.

Genetic factors are known to influence the risk of developing MS. In the past year, ACP Repository samples were used to study a specific gene that is associated with MS in women. Interestingly, cells in the immune system with this gene are more sensitive to Metformin (a drug commonly used to treat type II Diabetes). This exciting research will shed light on a genetic risk factor for relapsing remitting MS in women, and provide a biomarker for possible treatment with Metformin for female MS patients who have this gene. In 2018, investigators have also used ACP Repository samples and data to study genetic variations and modifiable lifestyle factors (smoking, obesity, low vitamin D levels, exposure to Epstein Barr Virus) and how they relate to the onset of MS and disease progression.

As previously mentioned, researchers using Repository samples must return their research results back to ACP for inclusion in the Repository database and for sharing with other researchers. In 2018, as in the past, returned data sets have been a valued resource for MS research. Much can be learned about how one’s genetics contribute to the MS disease process by studying patterns of gene expression during disease. This year, researchers re-analyzed returned gene expression data and identified several interesting changes that correlate with disease severity. These same researchers also plan to look at patterns of gene expression and how they change during disease progression.

ACP Repository samples can also be used to study other demyelinating diseases. Researchers have analyzed a broad range of different sample types from people with neuromyelitis optica (NMO) in order to better understand the genetic and biological basis of the disease. This groundbreaking work was published in May 2018. Results not only identify genetic risk factors for NMO, but also reveal two specific genes associated with NMO, which are not linked to MS. Furthermore, these data show NMO is more genetically similar to systemic lupus erythematosus (SLE) than MS.

These are just a handful of more than one hundred studies using the ACP Repository as a resource to advance and accelerate cutting edge research. Research on the genetics of autoimmune diseases is key to understanding disease processes, as well as identifying targets for new drugs. The identification of common autoimmune mechanisms holds exciting potential for discovery of drugs that may be useful in different disorders.
iConquerMS Spotlight – 2018 in review

People living with MS are the heart and soul of iConquerMS. A primary objective of the initiative is to enable all people living with MS to participate in research. Network members can not only contribute data about their MS experience, but also steer the direction of research by contributing their ideas. Ideally, tens of thousands of people from all parts of the country, from all backgrounds and ethnic groups, and of all ages and stages of living with MS will participate. This diversity will create a rich, interactive resource for MS research. This innovative program has made significant progress toward realizing this vision. In 2018, the network has grown to over 4,700 registered members living with both relapsing remitting and progressive forms of MS. In February, data was presented at the ACTRIMS Forum 2018 summarizing and comparing the characteristics of participants in the iConquerMS network. These data reveal interesting differences in the ranking of symptoms, functioning and quality of life across the different forms of MS, reinforcing the network’s value as an excellent resource for research.

REAL MS™ (Research Engagement About Life with MS) is an ongoing study of MS that was launched by iConquerMS two years ago. Study participants periodically complete questionnaires about their MS experience through the iConquerMS portal. These data are a growing and powerful resource for MS research, providing investigators and clinicians with real-life information on what living with MS is like. We’ve learned many interesting things from the data contributed by iConquerMS members, and look forward to learning more in the future! As another year draws to a close, we’d like to say thank you to those who have participated in iConquerMS and REAL MS. Two rounds of surveys were released in the last year (for a total of five rounds), one in March and one in September. To date, more than 60% of the iConquerMS community has completed at least one REAL MS survey (upwards of 2,800 people). The wealth of information provided may be key to unlocking the mysteries of MS and other demyelinating diseases. Let’s keep the momentum going! If you aren’t already a member of iConquerMS, please consider joining this powerful network and start completing your REAL MS surveys today! Already completed yours? Stay tuned for the next round!

iConquerMS has collaborated with researchers and organizations to enable and accelerate 11 research initiatives since its inception. STEP for MS (Supervised versus Telerehab Exercise Program for People with Multiple Sclerosis) is one such initiative, launched in 2018. This four-year study compares the outcomes of a 16-week exercise program conducted either at home, or in an exercise facility. The iConquerMS portal is being used for data collection, and to communicate with participants. The investigators leading STEP for MS hope the evidence generated in the study provides people living with MS information to guide their choice of exercise options. Interested in joining the study? Contact information, as well as criteria for participation, can be found
on the STEP for MS website. This study is just one of the many ways iConquerMS is facilitating and accelerating research on topics of importance to people affected by MS.