Dear Friends,

President Clinton signed the first National Family Caregivers Month Presidential Proclamation in 1997 and every president since has followed suit by issuing an annual proclamation recognizing and honoring family caregivers each November. In President Barack Obama’s words, “Family members, friends, and neighbors devote countless hours to providing care to their relatives or loved ones. During National Family Caregivers Month, we recognize and thank the humble heroes who do so much to keep our families and communities strong.” Providing support to a person with MS is both challenging and unpredictable. MS Caregivers are often unable to predict the onset of a relapse, the progression of the disease, or even the functional ability of their loved one over the course of a day. The day-to-day wear and tear of fulfilling this role can really add up. Our first article contains more information on caregiver burden, including tips and resources that can help make this important job easier.

The purpose of medical research is to advance knowledge about and find better ways to treat and prevent disease, thereby improving public health and quality of life. Ironically, those who potentially have vital input and are most affected by research results are not typically central to the process. MS caregivers and their loved ones affected by MS live the experience of the disease. A caregiver’s perspective is unique as they are the closest and most constant observer of the person living with the disease. His or her 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. Our second article details the importance of caregiver inclusion in research, as well as caregiver-focused research.
The National MS Society and the Accelerated Cure Project (ACP) share common goals in the fight against MS. Read more about how the two organizations will join forces moving forward to speed the pace of research toward better treatments and a cure.

As featured in our August 2017 newsletter, Freda Spector Warrington is a published author whose life was touched by MS when her daughter was diagnosed while a college student. Freda recently published her second book, “LISTEN TO THE LIGHT, The Daughter’s a Farmer.” This true story describes the journey of a mother and a daughter moving gradually toward mutual understanding and respect for each other’s world perspectives and life choices, including lessons learned and insights gained that surprised them both. The Mother and The Daughter, different in many ways, find their common ground in the values they share and the strength they possess. The last half of the book includes a compilation of holiday letters of The Daughter. Warm, wise and hilarious, The Daughter’s fans wait for and save these letters in real life. By choosing to use the generic terms, “The Mother” and “The Daughter,” the author underscores the universality of the themes so brilliantly illuminated in this fine and touching book. Warrington is generously donating profits from the sales of both of her books to ACP. Her donations are matched by the HERO Fund from Shell Oil Company. Consider giving one of Freda’s books to a friend or loved one this holiday season. Your gift will warm a heart and benefit MS research at the same time!

Our Repository Spotlight features recently published, groundbreaking work on the genetics of neuromyelitis optica (NMO) using ACP Repository samples. Results from this study 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.

Our iConquerMS Spotlight highlights REAL MS. The most recent round of surveys will only be available for completion until November 26th. If you haven’t already done so, please complete yours today! If you aren’t already a member of iConquerMS, please consider joining this powerful network. Our goal is to provide researchers with the most accurate representation of the entire MS population possible. Maximizing enrollment and participation in REAL MS will result in a clearer picture of what living with MS is really like. Every piece of data expands the pool of information that researchers can draw from.

Your support of ACP’s programs makes a significant impact on research into MS. We invite you to share the ACP newsletter with anyone you think may be interested.

The Accelerated Cure Project Team
Caregiver burden – What counts is how you carry it

MS is a chronic, unpredictable, often disabling disease that attacks the central nervous system. Symptoms can vary dramatically from person to person. The majority of people with MS are initially diagnosed with relapsing remitting MS (RRMS), which means their symptoms flare up at times and then return to baseline. Most people who are diagnosed with RRMS eventually transition to a secondary progressive course in which there is a progressive worsening of symptoms over time. As symptoms progress, or flare, the person with MS may be unable to perform their usual activities. At this point, responsibility for completion of these activities must shift to someone else, a caregiver.

The role of the caregiver for someone living with MS may change as symptoms progress. Early on, they may have to provide support for temporary flares and then enjoy periods of time symptom free. As MS progresses, it becomes increasingly disabling and the symptoms that once faded (or remitted) after a flare may become more permanent. When a person with MS is in remission, there may be less caregiving required, whereas when someone in in the middle of a relapse, caregiving may be a round-the-clock requirement. The unpredictability of MS affects the caregiver in a way unlike other chronic diseases. Caregivers are often unable to predict the onset of a relapse, the progression of the disease, or even the functional ability of the patient over the course of a day.

In some cases, MS caregiving is physical work as the disease can affect vision and mobility. For example, a person with MS may need help standing up, walking, getting out of bed, taking a shower, dressing, or getting on and off the toilet. MS can also affect cognition and memory, leading to more widespread effects including a loss of intimacy or losing the ability to work and communicate effectively. Recognizing that every situation is unique, people are generally forced into different roles in their lives when chronic illness or disability strikes. The individual providing assistance typically takes on added responsibilities, while the recipient loses independence. Providing care to a loved one can bring individuals closer. However, it can also put a strain on relationships, especially if changes aren’t welcome and affect future plans. Adjusting to new roles is challenging, but adjusting to unwanted ones is even more so.

Caregiver burden is defined as “the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member.” It is a response to the physical, psychological, social, and financial stressors associated with the caregiving experience. Caregiver burden can be both objective and subjective. Objective burden refers to the tasks required to provide care. Subjective burden is the extent to which the caregiver “minds” performing them. No matter how it is categorized, increased caregiver burden can have a profound impact on the care provider and recipient. Without proper training (for example, lifting or transfer techniques), the physical aspect of providing care to an individual with more advanced disease can potentially lead to injury. The cognitive effects of MS (problems with memory, attention or information processing) are far reaching. Both the
physical and cognitive effects of MS add to caregiver burden and have a rippling effect on the lives of those involved.

A 2011 study revealed some interesting facts about caregiver burden. Researchers contacted MS participants in the NARCOMS Registry requesting their assistance in identifying and recruiting their “informal caregiver” for the study (the person who provides the majority of unpaid care to help cope with the effects of MS on daily life). Data was collected via telephone interview from 530 caregivers to people living with MS. Results of the study revealed a direct relationship between caregiver burden and recipient’s overall health (burden levels were higher if the person with MS wasn’t feeling well, and vice versa). In addition, caregiver burden was directly related to the frequency of bladder dysfunction in the person receiving assistance, the number of hours per week spent providing assistance, and the extent to which caregiving responsibilities restricted the caregiver's ability to participate in activities that were important to them. Researchers also concluded that caregiver burden was significantly greater among men than among women, and that caregivers of either gender assisting males with MS experienced significantly greater burden.

Another study concludes that psychiatric symptoms and cognitive impairment in MS have a greater influence on caregiver distress (and reduced quality of life) than physical disability. Results show depression in a person with MS (the most common psychiatric symptom) directly impacts depression in their caregiver. Further research proves the reverse is also true. Depression in an MS caregiver is associated with the physical and emotional health of the person with MS receiving care. Investigators in the first study demonstrated this reciprocal relationship for other psychiatric manifestations of MS, such as irritability, aggression, delusions and dis-inhibition. These conditions are often difficult to manage and may lead to social isolation for both partners, straining their relationship and possibly leading to worsening symptoms. In this light, it’s not surprising that data showed these were the most disturbing psychiatric symptoms for caregivers.

The National Alliance for Caregiving (NAC) is a non-profit coalition of organizations focused on advancing family caregiving through research, innovation and advocacy. In 2012, they conducted a survey of 421 individuals who provided care to a friend or family member with MS. Results indicate caregivers spend an average of 24 hours per week taking care of their loved one and the impact on their lives is mixed. The positive effects are mostly related to relationships between the care recipient and other family members. For example, just over half of the respondents said that caregiving brought them closer to their children.
According to the survey, the most common negative impacts of providing care are on finances (22% of respondents had lost a job and 17% reported being unable to hold down a job due to caregiving), the ability to participate in hobbies, and issues with mental health. Almost half of respondents felt they did not have a choice in taking on the caregiving responsibilities. Those indicating they had a choice generally felt fewer negative and more positive impacts than those indicating they didn’t have a choice. Half of respondents to the NAC survey reported being physically exhausted and nearly one-third were physically injured as a result of providing care. According to the NAC survey, almost three quarters of the people living with MS receiving care have emotional or cognitive symptoms. Caregivers providing care to those with cognitive impairment were more likely to feel negative impacts from their role. Finally, those providing care to loved ones with frequently changing symptoms generally provided slightly more care in terms of number of hours. Many reported feeling relief and appreciation when their care recipient’s symptoms eased up, yet were also constantly worried that their care recipient would take a turn for the worse and they wished their care recipient’s symptoms were more consistent or stable.

Caregiver burnout is “a state of physical, emotional, and mental exhaustion and distress that may be accompanied by a change in attitude – from positive and caring to negative and unconcerned.” It is the unfortunate result of high levels of burden over an extended period of time. Understandably, this has dire consequences for administering care. Recognizing the signs of caregiver stress is important. Physical signs may include fatigue, exhaustion, trouble sleeping, decreased strength and endurance. One should also watch for psychological or emotional symptoms, such as irritability, anger, depression, inability to concentrate, memory problems, social withdrawal, and feelings of isolation. This level of exhaustion is preventable by knowing the signs, proactively asking for help and having ways in place to reduce stress. It is important for a caregiver to know their strengths, where they may need help, and the resources available to them.
Helpful tips to avoid caregiver burnout

There are many ways to manage care provider’s load and avoid burning out. Providing assistance can be isolating so make sure you have a support system of people you trust to help you through the difficult and lonely times. Whether it is other caregivers, family members, friends, or a counselor, it is important to have someone that will listen to and support you. Do not be afraid to ask for help. Communicate with your friends and family so they are aware of your situation and suggest specific things people can do to help you. If this isn’t possible you can hire professional respite care to provide temporary caregiving while you rest and recharge.

It’s important to educate yourself. Knowing more about MS symptoms, side effects, and treatment options can help you feel more confident and in control. It will enable you to participate more fully in your partner’s healthcare decisions, and adapt more easily to changes in their treatment plan. Be open to new technologies that can help you care for your loved one. Try attending an MS function. Organizations like the National MS Society host educational events all over the country. These events are places to learn more about MS and meet other caregivers.

Good communication is key to decreasing caregiver burden. Attend doctor’s appointments and discuss your loved one’s plan of care with health care professionals, including risks and benefits of treatment options. Being able to express your needs during these visits is important. Be sure you understand the information you are given and don’t hesitate to ask questions, if you need to. Communicating with your partner about their needs, as well as yours, can help maintain a healthy relationship with them. It also enables you to effectively inform clinicians about changes in your loved one’s health and behavior, as well as better participate in health care decisions.

Staying organized can help keep stress to a minimum and free up more time to do the things you enjoy. Ways to stay organized might include keeping a journal to track your partner’s MS symptoms or medication side effects, among other things. Calendars can be useful for appointments, or to keep track of when to give medications. Keep a list of important phone numbers handy. Organize medical information so it is up-to-date and easy to find. In general, it’s a good idea to make sure legal documents are in order.

Caregivers frequently forget to take care of themselves. The phrase, “you can’t pour from an empty cup” rings very true in this circumstance. If you don’t take the time to attend to your own needs, you run the risk of becoming depressed, having feelings of resentment toward your loved one, or losing other relationships. These are just a few consequences of putting your own health and wellbeing second to your role as a caregiver. Maintain your physical health by eating well, and getting plenty of sleep and exercise. Make time for your medical checkups and other appointments. Your mental health is important, too. Schedule time for yourself to refresh and do things you enjoy. If stress is a problem, a variety of therapies might help, including massage, prayer, yoga, or music therapy. Other activities that may help to stay grounded are exercising or simply spending time with a family pet. It’s important to watch for signs of depression and don’t delay getting professional help if you need it. Above all else, keep a sense of humor and don’t be too hard on yourself, it helps to lighten the stress of the moment and long term.
Will Researchers Listen to Caregivers?

The purpose of medical research is to advance knowledge about and find better ways to treat and prevent disease, thereby improving the public health and quality of life. This is achieved through a step-by-step process in which an investigator defines the topic or question to be addressed, develops a research plan, implements the plan and collects relevant data. Once data collection is complete, the data are analyzed and scientists report.

There are a number of excellent resources for caregivers that offer information and support free of charge. Founded in the late 1970’s, the Family Caregiver Alliance (FCA) is the first community-based nonprofit organization in the country to address the needs of caregivers. FCA’s Family Care Navigator provides state-by-state resources for caregivers, including respite providers. The National Multiple Sclerosis Society (the Society) hosts the MS Navigators program which also connects those providing MS care to valuable resources, such as emotional support services, and wellness strategies. In addition, the Society offers a helpful guidebook, Caring for Loved Ones with Advanced MS: A Guide for Families, which covers every aspect of MS, from reducing stress to management of MS symptoms. The Caregiver Action Network (CAN) is a nonprofit organization that provides education, peer support and resources to family caregivers across the country. CAN resources include an online caregiver forum. This is a good resource if you want to share a piece of advice, or if you feel isolated or depressed and want to talk with others going through the same experience. Featured in our August 2017 newsletter, Can Do MS offers the Embracing Carers webinar series. This informative series contains 3 relevant webinars addressing such topics as managing mood and cognitive changes in your loved one, prioritizing your emotional and physical wellbeing, and building a satisfying partnership.

In the event of an emergency on an airplane, an oxygen mask drops in front of you. The first safety instruction is to put your own mask on before assisting anyone else. The same principle applies for caregivers. Self-care is one of the most important, and yet one of the most often forgotten, things a caregiver should do. When your needs are taken care of, the person you care for will benefit, too. The day-to-day wear and tear of being an MS caregiver can really add up. By taking steps to educate yourself about MS, keep open lines of communication with your loved one and their healthcare providers, reduce stress and take care of yourself, you’ll find your burden may be lighter and you’ll have an easier time taking care of your loved one.
their findings. The hope is the original question can be more effectively answered with the knowledge gained. Medical research can take place both in the laboratory and clinical settings. Traditionally, people living with a disease have played a somewhat passive role in this process as the research subject, one who is “tested” and observed. Caregivers have generally played a more peripheral role, for example providing transportation to and support during appointments. Ironically, those who potentially have vital input and are most affected by research results have not historically been central to the process.

People living with MS and their caregivers live the experience of the disease. Their first-hand knowledge of the challenges, symptoms, and effectiveness of treatment is from the front lines. A caregiver’s perspective is unique as they are the closest and most constant observer of the person living with MS. His or her 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 include at every step of the research process.

As with the person living with MS, a caregiver’s intimate point of view can improve a study’s design in various ways. Their voice can inform an investigator’s approach and help identify knowledge gaps. The caregiver’s perspective can help ensure the research plan focuses on priorities that are relevant to individuals living with MS and assess the research plan’s feasibility. Caregiver feedback can help investigators develop research tools by pointing out inadequate descriptions or language that isn’t easily understood by a layperson. In addition, this information can help reveal any biases or assumptions researchers may have that could influence the research. Because researchers may be removed or isolated from the actual caregiver (or patient) experience, they may make certain assumptions that can lead to faulty interpretations. Those with direct knowledge of these topics may be the only ones able to help correct some assumptions. They may also be the best to explain and expand upon the implications of the research.

As far as study implementation goes, caregiver input may allow investigators to see where there may be difficulties in the process and help them adjust accordingly. The end result of which being the potential to minimize subject dropout rates and improve participant compliance to protocol, thereby improving data quality. Caregivers and people living with a disease, as “end users”, are generally the ones applying research findings individually or with healthcare providers. Involving them in the research process will facilitate and possibly accelerate application as the research may have more meaning, may be more relevant, or may be more easily understood.
The caregiver and patient voice are essential for data analysis and interpretation. Those living with the disease or condition under study can help identify themes that researchers might miss. This perspective can also help investigators check the validity and relevance of their conclusions. Many individuals find research daunting because the presentation of data is unclear. With the caregiver and patient perspective in mind, assessing publications can result in reporting that is more meaningful and understandable for all concerned. Most people are unaware of research unless highlighted by the media, or they specifically search for it. Published research articles are frequently behind pay walls, therefore inaccessible to the general public. As a result, many rely on media reports that may sensationalize findings or must put significant effort into seeking out research on their own. Those living with disease may know of more unbiased and efficient ways to communicate research findings, in addition to communicating this information themselves. These methods might use caregiver and patient-centered resources, for example social media, trusted newsletters, or forums.

The Research Loop is a web-based application designed to close the gap that happens after research is published and before new research starts, giving caregivers and people living with a disease a chance to take part in all aspects of the research process. The Research Loop allows the layperson to submit comments on published papers, which are then sent back to the researchers or funders of the research. Individuals can comment on everything from the study design, to the way the research was conducted, to the conclusions the researchers came to with their findings. With this feedback, researchers can then incorporate these ideas into their future projects. The Research Loop feedback form asks contributors to self-report where they encountered the research and how it affects them. This information can help researchers find areas where dissemination efforts are working and where they can improve. It can also indicate any issues with implementation and translation of findings into practice. Finally, the Research Loop website includes useful resources for those that would like to be more involved in research.

Comparative Effectiveness Research (CER) is intended to answer questions of importance to people living with a disease and their caregivers, and assist them with healthcare decision-making. In other words, it can be described as researchers doing research with patients, rather than for, at or to them. A recent study, published in the Journal of Comparative Effectiveness Research, reveals how caregivers, patients and clinicians currently feel about engagement as partners in health research. Online surveys were administered to study participants, including more than 2,000 caregivers and patients managing rare and chronic conditions, as well as over 600 practicing clinicians. Caregiver and patient involvement in medical research was defined on the survey as getting involved in other ways besides being research subjects. Approximately half of the caregivers and patients participating in the study reported interest in research engagement, particularly in helping researchers understand patient/caregiver points of view about needed information, helping investigators decide what questions to study, making findings easier to understand, and getting results to those who can use them. The most commonly cited factors influencing decisions to engage in research were the belief that participation could result in meaningful findings, feeling respected by the
researchers, and having an interest in the research being conducted. All participants endorsed the importance of improving patient care as motivating decisions to engage with researchers. Results of this study point to practical steps researchers can take to optimize the reach and value of CER.

In addition, to better partner with caregivers, researchers should make an effort to speak not only in patient-centered language, but also caregiver-centered language. For example, when discussing a protocol, study personnel should ask the caregiver whether or not he or she is willing and/or able to perform certain duties. Ideally, investigators should support the caregiver in figuring out the most effective and realistic way to comply with protocol requirements. It’s important for research personnel to explain jargon used in clinical research. In some cases, the caregiver needs to understand what the researcher is saying, so as to effectively communicate this information to the person living with the disease. Research personnel should guide the caregiver on being an effective observer, when necessary, clearly stating what to watch for, how to identify it and how to respond. For studies in which participants receive medical treatment, it’s important for researchers to prepare the caregiver and participant for the emotional aspect of ending treatment at the end of the clinical trial.

Pediatric studies most effectively model the optimal use of caregiver involvement. By necessity, pediatric specialists regularly interact with caregivers because, in the case of minor patients, the caregivers are the parents or guardians. Research participants must understand the purpose, risk and potential benefits in order to determine if participating in research is the best choice. Parents not only need to explain these risks to their child, but also must consent to their child’s participation. Pediatric studies cannot proceed without parent involvement. In most cases involving adult subjects, caregivers are not the ones authorizing participation in research. Even so, they are often needed to investigate and clarify the ramifications of participating, to ensure that their loved ones understand the risks and make informed decisions about participation. Caregivers must often drive their loved one to medical appointments, help them follow protocols, observe responses to study medications and procedures, serve as liaison to study personnel, and otherwise nurture and support their loved one throughout the clinical trial process. Investigators would benefit from studying the model of pediatric clinical trials, in the interest of optimizing support of the caregiver, and ultimately the best interests of the patient community. In short, researchers should design their protocols with the caregiver in mind.

The tide is changing with regards to involving caregivers and patients in medical research and drug development. In June 2018, the Food and Drug Administration (FDA) released guidance on Patient-Focused Drug Development (PFDD). The guidance consists of four documents, addressing in a stepwise manner how investigators can collect and submit caregiver and patient experience data for research. Recognizing that this valuable input can better inform medical product development, as well as regulatory decision making in the future, this series of documents is intended to facilitate the advancement and use of caregiver and patient
input. The Patient-Centered Outcomes Research Institute (PCORI) was created in 2010 with the passage of the Patient Protection and Affordable Care Act (often referred to as the “Affordable Care Act”). Recognizing the importance of engaging all participants in healthcare throughout the research process, PCORI is committed to producing and facilitating CER. PCORI’s mission is based on the premise that engagement of all stakeholders in healthcare can influence research to be more patient-centered, useful, trustworthy and ultimately reach the entire healthcare community. PCORI funded the development of PCORnet, the National Patient-Centered Clinical Research Network to accomplish its goals. PCORnet is made up of a number of partner networks, all working to further PCORI’s mission. As a member of PCORnet, Accelerated Cure Project launched the Multiple Sclerosis People-Powered Research Network (MS-PPRN), iConquerMS, in 2015. The initiative’s portal enables all people living with MS to play an active role in research. Another network, the National Alzheimer’s & Dementia Patient & Caregiver-Powered Research Network (AD-PCPRN), has put caregivers, along with patients, at its center. In dementia, a caregiver frequently administers treatments, ensures compliance with medications, and ultimately becomes the surrogate for patient reported outcomes. Meryl Comer, co-Principal Investigator of the AD-PCPRN, is a caregiver for her husband and mother, both of whom suffer from Alzheimer’s disease. She is a strong advocate for caregiver involvement in the research process. She sums it up nicely when she says, “Arm us with technologies and we can be your data collectors in place, in the home… Validate our observations instead of dismissing them. Let caregivers share the spirit of research with the knowledge that we are helping other families and the next generation…. I think that combination of technology with a mission that validates what we do every day in a very hopeless space will be empowering and I think it is something we can share.”

It’s also important to stress the importance of caregiver-focused research. 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. In this situation, over a long period of time, it’s conceivable that caregivers could become second victims of any extended condition. 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 investigate caregiver health and burden, as well as coping mechanisms and strategies. Learning more about these important topics would help sustain a vital relationship that is the backbone of many families.

Caregivers play an indispensable role in their loved ones’ lives. They may also play a pivotal role in medical research. By sharing their experiences of the daily burden of disease, their interpretation of unmet needs, and the types of research questions most important to them, patients and their care partners can transform the research process from one directed by sponsors and investigators to one driven by the needs of patients and their caregivers. This change in impetus has the potential to improve healthcare and outcomes not only for people affected by MS, but for the general population.
Joining Forces in the Fight for a Cure

The National MS Society (the Society) is an organization whose vision is a world free of MS. The Society mobilizes people and resources to drive research for a cure and to address the challenges of everyone affected by MS. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides programs and services designed to help people with MS and their families move their lives forward.

The Accelerated Cure Project (ACP) is an organization focused on accelerating research efforts to improve diagnosis, optimize treatment and ultimately cure MS. A core tenet in ACP’s mission is the belief that research is the only way to greatly improve the outlook and quality of life for people with MS. To this end, the organization promotes scientific collaboration and accelerates research by rapidly and cost-effectively providing researchers with data and samples they need to explore novel research ideas. As discussed in our June 2017 newsletter, ACP’s people-powered research network, iConquerMS\textsuperscript{TM} is a large and growing cohort for data-driven research into topics of interest for people living with MS. With more than 4,700 members, this robust network enables individuals affected by MS to participate in research in both common and novel ways. Participants may contribute their personal health data for research, join clinical studies, and engage with researchers to provide input into research study design. Members can also suggest topics of interest, helping to directly shape research and what is studied about living with MS.

ACP recently announced a powerful collaboration with the Society to facilitate their common goals. 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. From the patient perspective, Laura Kolaczkowski (Lead Patient Representative and Co-Principal Investigator of iConquerMS) shares, “We look forward to working with the Society to advance our shared goal: increasing the voice of people affected by MS in the research that impacts us. By growing the diverse
The leadership on both sides of this collaboration agrees on the impact it will have on MS research. According to Bruce Bebo, Ph.D., the Society’s Executive Vice President of Research, “We believe that research, and specifically research that keeps those living with MS at its center, is critical to reaching our bold vision of a world free of MS. We look forward to collaborating further with ACP and all that we can achieve together in supporting and advancing people-powered research in MS.” In Robert McBurney’s words (President and CEO of ACP and Co-Principal Investigator for iConquerMS), “The National MS Society serves a powerful community of people with MS, their care partners, loved ones, family and friends, as well as leading clinicians and researchers across the country. We are excited to expand on our existing relationship with the Society through this effort to increase the power of our shared communities in the fight against MS.”

Repository Spotlight – A whole-genome sequence study identifies genetic risk factors for Neuromyelitis Optica

ACP Repository samples include DNA samples from people with MS and other demyelinating diseases, including neuromyelitis optica (NMO). As discussed in our March 2018 and October 2018 newsletters, these samples have helped researchers identify the genes associated with MS. NMO is a rare condition that affects the optic nerve and spinal cord, once considered to be a clinical subclass of MS but is now known to be a distinct disease. NMO is similar to MS in that both are autoimmune diseases where the myelin sheath around nerves is damaged. The difference lies in the target of the immune attack. Researchers from Biogen, the Broad institute, Massachusetts General Hospital, Harvard Medical School and the University of Texas Southwestern (UTSW) recently published groundbreaking work on the genetics of NMO using samples from the ACP Repository and from UTSW. Results from this collaboration 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. Research on the genetics of autoimmune diseases is important from the perspective of understanding the pathophysiology of disease as well as identifying targets for new drugs.
The identification of common autoimmune mechanisms can result in the discovery of drugs that may be useful in different disorders. This is just one of more than one hundred studies using the ACP Repository as a resource to advance and accelerate research into demyelinating diseases.

### iConquerMS Spotlight – Last call for REAL MS surveys!

**REAL MS™** (Research Engagement About Life with MS) is an ongoing study of MS, launched by iConquerMS™ two years ago. Study participants periodically provide information about their MS experience by completing surveys through the iConquerMS portal. These data will play a crucial role in helping researchers and clinicians better understand the health and quality of life for people with MS over time, and will facilitate research into more effective, personalized treatments for MS patients. To date, 60% of iConquerMS members (more than 2,800 people) have completed at least one REAL MS survey. We are grateful for the wealth of information collected so far. It may be key to unlocking the mysteries of MS and other demyelinating diseases.

REAL MS participants have been invited to complete five rounds of surveys to date, the most recent of which was released in September. These questionnaires will be available until November 26th. **If you haven’t already done so, please complete yours today!** All iConquerMS members are invited to participate in REAL MS. Many of the surveys are quick and easy, some taking less than a minute to complete. If you aren’t already a member of iConquerMS, please consider joining this powerful network. Our goal is to provide researchers with the most accurate representation of the entire MS population possible. Maximizing enrollment and participation in REAL MS will result in a clearer picture of what living with MS is really like. Every piece of data expands the pool of information that researchers can draw from. According to Laura Kolaczkowski, Lead Patient Representative and Co-Principal Investigator of iConquerMS, “The power of so many of us coming together to share our experiences with MS in a way that can be measured and used by researchers can’t be overstated… REAL MS is the first real look at MS as it personally pertains to me, and others who live with this disease… I love knowing that when I see my children and grandchildren, I can say I did my best to help solve the question of MS by being part of REAL MS… This is a contribution I make that millions of people will benefit from, but especially my own family.”