Dear Friends,

Our May newsletter discussed the gender differences in multiple sclerosis (MS) from a woman’s perspective. This month we explore MS from a man’s point of view. Although men are three times less likely to develop MS than women, their disease course tends to be more severe. In most cases, men develop MS later in life and it typically follows a more progressive course. Our first article covers the current understanding of the role that testosterone plays in the development of MS and disease progression.

The role of a man as a bachelor, husband or father is seen differently in many families and cultures. To his partner, he may be a protector or a lover. To his child, he may be a role model or a caregiver. He may come from a traditional culture in which men and women are slotted into traditional roles, or a more modern culture where they are considered equals. All men should pay attention to their reproductive health, regardless of their circumstances. A healthy reproductive system not only affects overall health, it allows for a greater sense of fulfillment in many regards. Learn more about the ways MS and its treatments can impact a man’s reproductive health.

Recognizing there are exceptions, men generally see themselves as doers, fixers, and believe they should manage challenges on their own. They may approach MS analytically rather than
emotionally. Men tend to be more comfortable asking for information and less comfortable asking for help or support. As a result, they are slower to report symptoms or get evaluated for MS, and often slower to start treatment. They are more likely to wait until they are in crisis to seek help for issues. Our third article explores the challenges and emotions a man may experience in his walk with MS.

Dr. Farren Briggs has been keeping us up to date on trending topics in MS research through his column in the ACP newsletter since March 2017. Dr. Briggs won the Best Platform in MS Research Award at the 2018 annual meeting of the Consortium of Multiple Sclerosis Centers (CMSC) in late May. Read more about his innovative research, enabled by ACP Repository data, and this well deserved award.

Our Partner Spotlight this month highlights recent fundraising events, organized by some remarkable individuals who had fun and made a difference at the same time. Also included are some exciting upcoming events, and possibilities for using social media to help support ACP. We appreciate the dedication and hard work of our volunteers and staff to make these events happen and hope you’ll join us in the future!

Our iConquerMS Spotlight is on the recent collaboration between iConquerMS and the Italian MS Society to standardize and harmonize Patient Reported Outcomes (PRO) data. This merging of data across cultures and countries will result in a powerful tool that can be used in both the clinical and research settings. Our Repository Spotlight highlights the work of researchers at Biogen and UT Southwestern. Results from this study identified genetic risk factors for NMO.

We hope that you enjoy our newsletter and invite you to share it with anyone you think may be interested.

The Accelerated Cure Project Team
Does Testosterone Protect Against MS?

Although men are three times less likely to develop MS than women, their disease course tends to be more severe. There are also gender differences in the age of onset and subtype of MS. Women generally develop the disease at a younger age and usually have a relapsing-remitting course. In most cases, men develop MS later in life and it typically follows a more progressive course. Researchers are working to better understand the role that testosterone plays in the development of MS and disease progression.

Researchers at the Partners Multiple Sclerosis Center at Brigham and Women’s Hospital in Boston are conducting the CLIMB study (Comprehensive Longitudinal Investigation of Multiple Sclerosis) to, among other things, observe testosterone levels in men with MS. This is a large-scale, long-term study of patients with MS. Subjects in the study have neurological exams and MRI scanning performed on a yearly basis. They also donate blood samples and complete quality of life and mood questionnaires at the same interval. Interim results from the study, published in 2006, revealed that a large proportion of men with MS have low testosterone levels. Recent research has shown reduced testosterone is, in fact, a risk factor for MS in males and lower levels may impact MS risk as early as the prenatal period. After the age of 30, most men begin to experience a gradual decline in testosterone. The delayed development of MS in men is thought to correlate with age-related reduction of testosterone levels. Data from the CLIMB study also reveals a potential association between low testosterone levels and increased disability.

The question is: Would testosterone be an effective treatment for MS? Researchers have shown that testosterone has a neuroprotective effect in animal models. A small pilot study in male MS patients at UCLA demonstrated that testosterone therapy led to significant improvements in cognitive function and slowed brain tissue loss. However, larger placebo-controlled trials are needed to confirm these preliminary results.
Testosterone therapy is known to have other benefits, however it is associated with significant risks and undesirable side effects. Men have reported such benefits as an increase in muscle mass and strength, improved bone density, less fatigue and improved sexual function. Older men treated with testosterone have also shown improvement in memory and cognitive function. However, these beneficial effects must be weighed against possible serious risks. These include an increased risk of hypertension and heart disease, increased hemoglobin (the oxygen-carrying cells in the blood), increased risk of cancer or worsening of preexisting cancer, and emotional instability. Testosterone therapy also has a long list of other noteworthy side effects ranging from addiction to a reduction in sperm count (which can lead to infertility).

Researchers have recently uncovered a testosterone-regulated pathway associated with demyelination that could hold the key for new treatments for MS. Investigators at Northwestern University identified a “guardian molecule” in a mouse model of MS called cytokine IL-33 (IL-33) that appears to protect males from disease. The immune system of an individual with MS overproduces a type of immune cell called T helper 17 cells (Th17), which can directly attack the myelin sheath. Researchers found that, in male mice, testosterone resulted in the production of IL-33, which was seen to trigger a pathway that prevented the production of Th17. Furthermore, when female mice with disease were treated with IL-33, their symptoms were eliminated. Recognizing that these results have yet to be replicated in human studies, scientists speculate that lower testosterone levels in women (which hypothetically are insufficient to activate this protective pathway) could be the reason MS is more prevalent in women.

There is a variety of disease modifying therapies approved for the treatment of MS. Most work by suppressing the immune system and leave patients more at risk for infection and feeling unwell. Treatment with testosterone is not a viable option for MS patients as its neuroprotective effect has yet to be confirmed and its risks outweigh its benefits. However, the newly discovered pathway testosterone regulates holds great promise in the development of more targeted therapies. Finding a way to activate IL-33 production or emulate this pathway through an approach other than testosterone could revolutionize MS treatment.
What is it like being a man with MS?

Men differ from women in how they experience MS, both physically and psychologically. Men tend to have a more progressive disease course and a more rapid accumulation of disability than women do. Men with MS typically have fewer relapses, but the relapses they do have are more likely to affect motor function and less likely to be sensory in nature. In addition, men generally have a poorer recovery after their first disease relapse than women. This could be due to the fact that men are slower to report symptoms or get evaluated for MS, and often slower to start treatment. They are more likely to wait until they are in crisis to seek help for issues. There doesn’t appear to be a difference in treatment effect between men and women. Men have a greater tolerance for risk and are more likely to opt for more aggressive treatments, however they tend to be less compliant to a treatment regimen.

The emotional needs of men are different from those of women, whether they have MS or not. Recognizing there are exceptions, they generally see themselves as doers, fixers, and believe they should manage challenges on their own. As such, men with MS tend to want to fix the disease themselves. Many men approach MS analytically rather than emotionally. They tend to be more comfortable asking for information (with the exception of directions) and less comfortable asking for help or support. Men generally don’t talk about emotions and problems. Some men with MS may experience certain symptoms they find too embarrassing to talk about, or that challenge their masculinity (for example, sexual difficulties).

Traditional gender roles typically place the man in charge of taking care of his family, being the breadwinner of the house, and protecting his loved ones from danger. Many men with MS find there are things they are not physically able to do anymore. The feeling of being helpless or being unable to do something on their own may be very difficult in the mindset of a man, of what he feels he should be able to do. The conflict begins when a man’s accumulated disability level reaches a point where his expected roles become challenging or even impossible, requiring someone else (often his partner or spouse) to take the lead. For example, in later stages of MS, many people can no longer work (or at least not as much or as hard as they could before) putting the financial responsibility on their significant other. For a man who is used to being the primary or at least equal breadwinner, no longer being able to work may result in him feeling like a failure or inadequate. Even in today’s changing world, these traditional stereotypes still ring true for many men.
Research shows that men tend to use the healthcare system less frequently than women and engage in fewer preventive health behaviors (younger men, in particular). Many believe this is the result of men's long-established socialization to appear tough, stoic, independent and resilient.

Gender differences exist in the self-efficacy of those living with MS. This is the belief in one’s ability to succeed in specific situations, or accomplish a task. One study showed that women have a significantly greater belief in their ability to function with MS than men. The findings also indicated that men with progressive forms have less faith in their ability to control their MS and function with it than those with relapsing-remitting MS (RRMS).

Other studies have demonstrated divergence in the impact of MS on health related quality of life (HRQOL) between men and women. The impact of disability on all aspects of HRQOL (physical and social functioning, as well as emotional wellbeing) was higher for men than women. This research indicates that, despite physical impairment, women with MS appear to maintain psychological and mental wellbeing to a greater extent than men.

A large-scale study found that anxiety and depression are common in people with MS. According to this study, women struggle with higher levels of anxiety than men and men are more likely to be depressed than women, especially men with RRMS. Group therapy aims to improve the psychological wellbeing of those wrestling with these issues. Participants often find their emotional and mental health is improved through contact with others in a similar situation. Men may benefit from support groups, however they are less likely to express a need for and seek support than women. There are also various online forums for men with MS. However, many men stop participating because they don’t like to talk about certain aspects of their lives they would consider private and/or embarrassing to talk about.

Traditional stereotypes prove to be all too true for men living with MS. These preconceived notions tend to get in the way of many getting the support they need. There is a need for health care professionals to take the male perspective into consideration so they might tailor their support programs to better meet men’s needs. Any intervention or program must take into account the type
of support that is offered to men and consider that for some, retaining a sense of masculinity may be more important than seeking assistance. There is also a need to educate men about support groups and de-stigmatize the decision to seek support. Further research is required to better understand what program strategies would be most effective to provide support for men with MS.

**Multiple Sclerosis and Becoming a Dad**

The role of a man as a bachelor, husband or father is seen differently in many families and cultures. To his partner, he may be a protector or a lover. To his child, he may be a role model or a caregiver. He may come from a traditional culture in which men and women are slotted into traditional roles, or a more modern culture where they are considered equals. All men should pay attention to their reproductive health, regardless of their circumstances. A healthy reproductive system not only affects overall health, it allows for a greater sense of fulfillment in many regards. Multiple sclerosis (MS) and its treatments can impact a man’s reproductive health in a number of ways.

Sexual dysfunction (SD) is an issue that most men struggle with at some point in their lives, whether they have MS or not. SD is common in men with MS and may occur at any stage of the disease, even without severe disability.

The ways in which MS can affect sexual function can be divided into three categories: primary, secondary, and tertiary SD. Sexual arousal begins in the central nervous system, as the brain sends messages to the reproductive organs along nerve pathways in the spinal cord. Primary SD stems directly from demyelination of these nerve pathways that affect the sexual response. In both men and women, this can include a decrease or loss of sex drive, altered genital sensations, and problems having an orgasm. Men may experience erectile or ejaculatory dysfunction. Secondary SD is caused by MS symptoms that do not directly involve nerve pathways to the reproductive system, but still have a negative impact the sexual response. Symptoms that may cause secondary SD include bladder and bowel problems, fatigue, spasticity, or sensory changes. Tertiary SD results from the emotional factors related to living with MS. These may involve loss of self-esteem, depression, anxiety, anger or the stress of living with a chronic illness. In a long-term relationship, MS can sometimes cause role reversals that can affect a
couple’s sex life. MS can also lead to other stresses, such as job loss, that can change the experience of sex for an individual or couple. These powerful feelings have the potential to contribute to SD as much as, or possibly more than demyelination of nerve pathways.

Erectile dysfunction (ED) is one of the most common symptoms of MS in men, affecting up to 91 percent. Nerve demyelination is one of its many causes. Erections occur when signals from the brain cause the muscles of the penis to relax, allowing blood to flow into two chambers on the underside of the penis. The increased blood supply causes the penis to swell and become rigid. Erections happen in response to either sexual arousal or physical stimulation of the penis. These are important distinctions as they involve two different mechanisms: Erections that occur in response to erotic thoughts or visual cues are processed by the brain and travel down the spinal cord to trigger an erection. Erections that happen as a result of genital stimulation only use nerves in the lower part of the spinal cord. Depending on where the demyelination occurs, the cause and symptoms of ED can vary. For example, some men may be able to achieve an erection in response to physical but no visual stimulation, or vice versa. It’s important to note that ED can be caused by a number of other factors, including stress, mood, high blood pressure, obesity, diabetes, bladder and bowel dysfunction, excessive alcohol use, and certain medications.

ED can be treated with oral medications, such as Viagra®, Levitra®, or Cialis®. As an alternative to oral ED drugs, injectable medications such as alprostadil, papaverine, and phentolamine can often enhance erection by increasing blood flow in the penis. In cases of severe ED in which other options have failed, penile implants can help. When considering treatment options for ED, it’s important to consider its contributing factors. For example, abnormal sensations can often be controlled through use of other medications. For those with urinary problems, intermittent catheterization may be used to control urinary leakage during intercourse. Anticholinergic medications, which are often used to treat urinary dysfunction, are also known to cause ED. In some cases, psychological factors related to mood or self-esteem play a role in ED and should be addressed separately. It’s important to note that antidepressant medications may also cause or contribute to ED.

Between 35 and 50 percent of men with MS experience problems with ejaculation. These problems may include premature, delayed or retrograde ejaculation, or not being able to ejaculate at all.
Although the treatments described above can help with ED, there are no treatments that help with ejaculatory dysfunction. While a man’s sexual performance may be improved by being able to maintain an erection for longer, ejaculation may remain a problem.

Sexual problems can be demoralizing for men. Many find it difficult to talk about them, even with their significant other or doctor. It is important to discuss them, however, especially with your partner. Sharing with your loved one may bring you closer and help resolve concerns relating to sexual intimacy. Often the strain of living with MS can challenge a couple’s efforts to communicate with each other about their needs. Individual or couples therapy can help both partners work on sources of stress or depression that may interfere with sex, improve communication, and facilitate ways to be more supportive of each other.

Male fertility does not appear to be impaired in MS, although ED and ejaculatory dysfunction may interfere with a man’s ability to conceive a child. As discussed earlier, ED can be treated with a number of medications and therapeutic strategies. Couples dealing with ejaculatory dysfunction have been able to successfully conceive a child with the help of such techniques as penile vibratory stimulation or electronic ejaculatory stimulation, followed by artificial insemination. Men who are concerned about fertility issues should consult a urologist experienced in this area.

When a man with MS considers having children, he may question the safety of any disease-modifying therapy he may be taking. The areas of possible concern with MS medications are they may affect either the quality or quantity of sperm, transfer chemicals that could affect the fetus, or cause mutations. This is an important topic to discuss with one’s healthcare team. Researchers have gathered a lot of information in this regard, however they still have much learn. No adverse side effects for the unborn child have been reported with a father’s use of beta-interferon (Avonex, Betaseron, Extavia, Plegridy or Rebif) or glatiramer acetate (Copaxone). There is no information to date on the reproductive side effects of Tysabri or Gilenya in men. There are some data to suggest that mitoxantrone (Novantrone) and cyclophosphamide (Cytoxan) can harm sperm. Men who want to have children and plan to start treatment with either of these medications should consider freezing healthy sperm ahead of time. Dimethyl fumarate (Tecfidera) has been associated with reproductive toxicity in animal
studies, however it isn’t known if this is relevant in humans. In order to be drug-free at conception, men need to be off MS treatment for about 10 weeks, as it takes approximately 70 days for the body to produce new sperm. The exception is Aubagio, which can be detected in human semen and takes a very long time to be eliminated from the body. If a man is taking Aubagio, it’s recommended that he stop taking it and undergo an accelerated elimination procedure to remove the drug from their systems (in addition to the 70-day clearance time), or wait two years before they try to conceive. Prednisone and methylprednisone (Solumedrol) are often used to treat MS relapses. Of note, these medications are known to cause decreased sperm count.

Despite the obstacles men may face on the road to parenthood, there is good news. MS in men has not been associated with spontaneous abortion, low birth weight, or premature birth. It’s important for men living with MS to work with their partners and their healthcare team toward maintaining optimum reproductive health. Overcoming the barriers that MS presents with regards to intimacy allows for a more fulfilling personal experience and opens the possibilities for a rich family experience. As former Red Sox player, Wade Boggs, described his relationship with his father, “Anyone can be a father, but it takes someone special to be a dad, and that’s why I call you dad, because you are so special to me. You taught me the game and you taught me how to play it right.”

The ACP Repository – “A unique resource that creates a lot of unparalleled opportunities to look at many different questions”

Dr. Farren Briggs has been keeping us up to date on trending topics in MS research through his column in the ACP newsletter since March 2017. Farren is an Assistant Professor in the Department of Population and Quantitative Health Sciences in the School of Medicine at Case Western Reserve University. His research focuses on the epidemiology of multiple sclerosis (MS), including understanding genetic drivers of the disease to healthcare utilization patterns. When asked what sparked his interest in the epidemiology of MS, Farren states, “I was first interested in biostatistics, but then I discovered epidemiology.
realized that I didn’t want to just answer questions, which is what biostatisticians do… I wanted to ask the questions relevant to understanding human health and disease. As for MS, I happened into a project studying smoking in MS, and the more I read, the more I realized how little was known of the underlying mechanisms contributing to MS – and I saw the tremendous need and opportunities to do important work.”

Dr. Briggs’ recent research focuses on the impact of obesity on the early clinical presentation of MS. Using data from approximately 1,500 participants in the ACP Repository, Farren examined the relationship between established MS risk factors (things associated with the onset of MS), such as smoking status, obesity, history of infectious mononucleosis, education level (a proxy for socioeconomic status), and genetic risk factors. He hypothesized if these things affect the onset of MS, they likely also influence other aspects of MS early in the disease process, such as the age of onset; the time between first relapse and second relapse; the diversity of symptoms at onset; and the number of relapses in the first two years (disease activity). Data showed obesity was associated with an older age of onset, increased diversity of symptoms at onset (meaning more symptoms across various systems), shorter times between the first two relapses, and 25% increase in early disease activity. In Farren’s words, “These things have not really been explored before, and it’s important to investigate factors influencing early disease as it might be suggestive of factors influencing long-term outcomes. I looked at obesity because it has recently been established as a risk factor for MS (in the last 3 or 4 years) – and it is something modifiable… We had a wealth of information that was available through ACP that we considered in these models. We ran four models, one for each of the outcomes, and surprisingly, obesity was associated with all of them.”

Dr. Briggs presented these data at the 2018 annual meeting of the Consortium of Multiple Sclerosis Centers (CMSC) in late May. Each year poster and platform presentation awards are given to researchers doing unprecedented high caliber research. These are studies that can be applied to clinical practice and benefit the comprehensive care of MS patients. Dr. Briggs was awarded the Best Platform in MS Research Award at this year’s meeting for his presentation of these findings.

These interesting results warrant further study into the impact of these and other characteristics that influence MS diagnosis and disease progression. However, according to
Farren, further study in this area will be a challenge. In his words, “There are very few data sets that have the wealth of information to replicate these associations, hence the importance of the ACP Repository and iConquerMS. The ACP Repository is unique because it has several aspects that are really rare. Generally, you’ll find large studies of MS that have only genetic information, you’ll have several studies that have clinical data, and a few with environmental history and more nuanced questions. Here we have all three data types captured within one single data set. It is quite a unique resource that creates a lot of unparalleled opportunities to look at many different questions.”

**Fundraising For a Cure**

Volunteers make a huge difference in ACP’s success. We are grateful for hundreds of donated hours that support our work each year. Our volunteers help us with a wide variety of important tasks, both in the office and remotely. Some of our volunteers give of their time and talents to host third party fundraising events to benefit ACP. Highlighted below are recent fundraisers, organized by remarkable people who had fun and made a difference at the same time!

**Exercising For a Cure – Cressey Sports Performance Boot Camp**

Anna Sweeney was diagnosed with MS 17 years ago, when she was 15 years old. According to Anna, “I was playing basketball one day, and I thought I had dislocated my shoulder because my hand went numb.” She and her family went to a neurologist, who recommended an MRI. After reviewing the scan results, the neurologist informed Anna that the cause of her numbness was MS. In trying to learn more about the disease, Anna’s family became very involved with what was then the Boston Cure Project (later renamed Accelerated Cure Project (ACP)). They did a significant amount of outreach to other newly diagnosed families, fundraised for BCP, and her father served on the Board of Directors.

Today, Anna is a registered dietitian. Exercise is an important part of her regimen. With the guidance of her personal trainer, Frank Duffy, she works out at the gym four times each week. Her determination and hard work are an inspiration to Frank. In his words, “It’s been really humble and inspiring to see what she does… She does all of the work. She’s making the difference. I’m just trying to give her the tools to make forward progress… For someone with such a bad hand dealt to them, she’s one of the most positive human beings I know.” Cressey
Sports Performance holds Charity Strength Camps for organizations that are meaningful to the individuals who participate in their Strength Camps program. Frank states, “Since Anna’s been working with us, she’s come a long way. I suggested we put a fundraiser together for whatever she wanted to do… ACP is the organization she wanted to work with. It’s the very least we could do as a group to try to give back.”

The boot camp event to benefit ACP took place on 4/28, and raised over $3,000. With 60 people attending, participants rotated between 4 stations (each directed by a coach), at which they did different exercises. When asked about the event, Frank said, “It pretty much doubled our biggest charity event to date… With our charity events, we have a decent amount of new people come in for the first time, so we try to keep it as simple as possible. We do a decent amount of body weight exercises and we throw medicine balls. We keep it simple, so people understand what we do, but also keep it fun and make sure nobody gets hurt in the process.” In Anna’s words, “The event was lovely. I’m super-grateful that it happened.”

When asked why she chose ACP as the organization to receive donations, Anna shares, “I would never spend time raising money for any other organization… I appreciate where the ACP started. I appreciate the space that you are moving us into. I feel like organizations like the ACP are going to be at the helm and the impetus in finding a solution for those of us who are living with this disease.”

Paddling For a Cure – The Essex River Race

Patrick Curley is a Certified Elder Law Attorney with Curley Law Firm LLP in Wakefield, MA. His love of rowing started when he joined the lightweight crew team at Dartmouth College. According to Patrick, “I had never heard of crew. In the first few days of freshman year, the crew coaches were at the cafeteria doors looking for people that fit the body shape for rowing…I was lean and tall so I fit the bill.” More than 25 years later, Patrick still loves rowing and paddling.
Over the last few years, Patrick has turned that athletic passion into a fundraising opportunity to benefit ACP. Patrick chooses the athletic competition, and ACP sets up a fundraising page so that his sponsors can easily support him and donate to ACP.

In 2014, he competed in the Essex River Race for the first time in a one-man rowing scull and raised thousands of dollars for ACP. Over the last two years, Patrick has paddled the race in a sea kayak. He raised more than $4,380 for ACP from this year’s race.

The race itself is a grueling six-mile race on a tidal river out of Essex, MA to the ocean and back. Patrick said, “I like challenging athletic events that aren’t traditional… It attracts a very interesting breed of participants. Many racers work or live by the sea – not always traditional athletes but tremendous competitors. I am in awe of my fellow competitors, most of whom are older than me. Part of the camaraderie and fun of the race is all of the different water crafts and people from different backgrounds.”

When asked why he fundraises for ACP, Patrick stated, “Because I’m an elder law attorney, many of my clients have MS and other chronic illnesses, and so it means a lot to me and my clients to raise funds for this important charity. No matter how hard the race is, it’s nothing next to what those living with MS may have to go through in their day-to-day life… I think ACP is the best organization to drive research toward better treatments and a cure, plain and simple… I think there are a lot of nonprofits in the MS space, but none of them have the fixation and focus and mission that ACP has to really accelerate toward treatments and a cure.”

Patrick hopes to participate in even more challenging rowing competitions in the future. In his words, “The Essex River Race is a lead-up to what’s called the Blackburn Challenge. Blackburn is a famous character in Gloucester, MA history. He was fishing in an open dory off Newfoundland in 1883 when he and his fishing partner were separated from their mother ship by a blizzard. Blackburn rowed five days without food or water towards shore. He made it but his hands had frozen to the oars. He lost all his fingers to frostbite but the Blackburn Challenge is raced every year in his honor. It is a 22-mile race around Cape Ann in open water, and a very tough, tough race. It’s on my bucket list for a future fundraiser for ACP!”
Scholarship and Fellowship For a Cure – The Medeiros Family Scholarship and Annual Event

Five members of the Medeiros family have been diagnosed with multiple sclerosis, including Nancy Medeiros and her late brother, Edmund. For the last 16 years, Nancy and her sister, Judy, have organized two charitable events in memory of their brother.

The Medeiros family annual event is a wonderful gathering of family and friends held at the Dante Club in Somerville MA. For a small entrance fee, everyone gathers to enjoy a buffet dinner, drinks and music. They offer over 30 raffle prizes and gift certificates. The proceeds from the evening benefit the Medeiros family scholarship and ACP. According to Nancy, “I never really thought about MS until I got it… My brother and I were diagnosed with MS at the same age, when we were 35 years old. He passed away 17 years ago in June… My sister wanted to do a scholarship in his memory and I wanted to do something for MS… We give two book awards of $500 each to Somerville high school students to use toward a college of their choice.” The remaining proceeds from the event are donated to ACP.

This year’s event was held on 4/21 and has raised over $1,800 to date. In Nancy’s words, “I promised my brother we were going to do this until we have a cure and I believe we will … we had a good crowd this year. I’d say at least 75 or so. Since day one we never know how many people are coming because maybe 5 or 6 people buy a ticket in advance. Everybody buys them at the door. It’s family and friends mostly … I tell people all the time, ‘it’s never too late to donate!’”

Nancy also volunteers for the National MS Society. She and her sister began fundraising for ACP when it was known by its initial name, Boston Cure Project. According to Nancy, “The MS Society is wonderful. I give them my time, I volunteer… But, I wanted to give money to ACP.” When asked why she raises money for ACP, Nancy said, “I wanted to choose something that was a small non-profit that didn’t make a lot of money… I liked the idea of ACP’s founder starting it himself … just knowing the passion he had and he focused on research… that’s why I chose ACP.”
We’d also like to let you know about some fun upcoming events this summer and fall. Stay tuned to future newsletters for updates!

**Driving For a Cure – Rally North America**

Hollie Schmidt, our VP of Scientific Operations, and David Gwynne, our Director of Alliances and Collaborations, will be participating in Rally North America 2018 US 50 West Rally this summer (July 8 – 12) to support and promote our efforts to treat, diagnose and cure MS. The Rally is an automotive scavenger hunt event that traverses three states. Rally teams will navigate their way to secret checkpoints & collect points for finding unique items/pictures along the way. Over 50 cars will be traveling from Pueblo, Colorado to Carson City, Nevada as part of the Rally.

Rally North America was founded in 2009 and has raised over $825,000 for charity since its inception. In 2014 Rally North America raised $110,000 for ACP. This year the rally’s main beneficiary is Concerns of Police Survivors (C.O.P.S), but ACP was invited to participate in the rally to raise funds for our important work and to be featured in a documentary style TV production to be aired on MAVTV in 2019.

Please consider supporting Hollie and David as they participate in the Rally and help them reach their fundraising goal by becoming a **sponsor** or by **donating**. Sponsorship levels are available to fit every budget!

**Sing For a Cure - Sing to Cure MS concert**

Marion Leeds Carroll is an experienced opera singer and stage director who lives in Arlington, Massachusetts. Since 2003 she has applied her talents and love of music to raising funds for ACP, a disease she has lived with since 1988. Every year on the last Sunday in October, Marion and a group of colleagues perform a concert at a local church, donating all proceeds to ACP. The Music to Cure MS concert features solo instruments and chamber music ensembles as well as singers. These professional-level musicians (all friends of Marion) perform a diverse repertoire of classical music. This
year’s concert will be held on Sunday, October 28, 2018, from 3-5pm at the Park Avenue Congregational Church in Arlington MA. Admission to the concert is free of charge.

The power of music is undeniable. It can relieve stress, bring back pleasant memories, or just help you smile. Mark your calendar and treat yourself to an afternoon of music. Please also consider making a donation to ACP on Marion’s behalf. Help the power of music accelerate our progress toward a cure for MS!

**Post For a Cure – Create a Facebook Fundraiser**

Do you have a birthday, wedding, or other special celebration coming up? Consider creating a fundraiser on Facebook to benefit ACP. It’s quick and easy to do, and can have a significant impact! On the top right corner of your Facebook profile there is a small arrow pointing downward. If you click that arrow, you will see “Create Fundraiser” in the drop down menu. Click “Get Started” and follow the prompts to create your fundraiser. In order to raise funds for ACP, you will need to select “Non-profit” and then search for Accelerated Cure Project for MS. Enter how much money you hope to raise, and the date your fundraiser will end.

Add a title and cover photo for your fundraiser, and include why you are raising the money. That’s all there is to it! Your friends will receive a notification inviting them to support your cause in honor of your special day.

We appreciate the hard work of our volunteers making these events possible. As you can see, the possibilities are endless for fundraising events! We are happy to work with you to organize an event around your favorite activity. Or, if you have a talent you would like to share with the community, we can help streamline the donation process so it can be a fundraiser for ACP, too. Funds raised from events like these help us to continue our work to improve diagnosis, optimize treatment and find a cure for MS. For more information on hosting your own fundraiser, contact Lindsey Santiago at lsantiago@acceleratedcure.org or (781) 487-0013.
**iConquerMS Spotlight – Italian MS Society**

iConquerMS™ and the Italian MS Society have entered into a collaboration to standardize and harmonize, across different cultures and countries, the collection of a core set of MS Patient Reported Outcomes (PROs) for use in care settings, research activities, patient self-management, and the development of new MS treatments. This initiative is focused on achieving a strategic goal of the International Multiple Sclerosis Federation. Two experienced organizations are now joining forces to ensure that the symptoms, abilities/disabilities and quality of life information are routinely collected and used to improve the health, healthcare and quality of life of people affected by MS. According to Robert McBurney, Co-Principal Investigator of iConquerMS and CEO of ACP, “Standardizing, and harmonizing the use of a core set of PRO measures for MS across countries and cultures will ultimately enable patients, physicians, regulatory agencies, and other stakeholders to ‘speak the same language’ worldwide about the entire experience of MS beyond standard clinical assessments, and for that information to be included along with clinical assessments in electronic health records and registries, in research studies, and as outcome measures in product development clinical trials.”

**Repository Spotlight – Biogen/UT Southwestern**

Researchers at Biogen and University of Texas Southwestern (UTSW) recently studied the whole genome sequence of a cohort of Neuromyelitis Optica (NMO) patients and healthy controls. Results from the study, published in the May 2018 edition of *Nature Communications*, identified genetic risk factors for NMO. According to Ben Greenberg at UTSW, “The results identified a low C4 copy number as a genetic risk factor for NMO. This pattern has been associated with SLE previously. Data from this study also helps to understand previous studies that focused on HLA (human leukocyte antigen – cell surface proteins responsible for regulating the immune system) risk factors and suggests that whole genome sequencing studies can yield unique results when compared to GWAS (genome-wide association) studies.” This work was done collaboratively across multiple centers, using ACP Repository samples. 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.
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