Dear Friends,

Theodore Roosevelt once said, “Far and away the best prize that life has to offer is the chance to work hard at work worth doing.” ACP believes that research is the only way to greatly improve the outlook for people with MS. ACP’s work facilitates MS research by providing researchers with the data and samples they need, as well as engaging the MS community and fostering scientific collaboration between investigators who share a common goal: improving treatments and finding a cure for MS. The causes of MS are unclear. 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 which leads to them developing MS. The ACP Repository is an unparalleled resource for studies aimed at understanding these triggers. Our first article explores some well-known and recently discovered risk factors for MS.

None of the FDA-approved treatments for MS are completely effective. As a result, many people with MS are turning to alternative treatments, such as cannabis, for relief of their symptoms. There are many open questions regarding marijuana use, including optimal strains, frequency of use, risks of long-term use, and which symptoms it effectively treats. iConquerMS™ was developed to engage people with MS to drive and shape research and to fuel research on topics, like these, of great interest to people living with the disease. Read more about what we currently know about, and the controversy surrounding this Asian herb.

The ACP team is comprised of a small group of hard working people. ACP’s Chief Operating Officer, Sara Loud, summed it up nicely when she said, “I love the small but mighty team we've built and the
commitment we share to doing great work with meaningful impact.” This month we would like to introduce you to our team.

Our Repository Spotlight features Dr. Bob Axtell, of the Oklahoma Medical Research Foundation. Dr. Axtell used ACP Repository samples to study the genetic and biological basis of Neuromyelitis optica (NMO). Returned results from Dr. Axtell’s studies, and other returned data sets, enrich the ACP Repository as a resource to advance and accelerate research into demyelinating diseases.

Our iConquerMS Spotlight highlights REAL MS™ (Research Engagement About Life with MS). The newly released Summer 2018 modules will play a pivotal role in accelerating research to determine ways to personalize clinical care by identifying factors that affect progression and treatment outcomes for MS patients.

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

**MS Risk – Can it be influenced?**

The causes of MS are unclear. It is generally agreed that some people have a genetic make-up that predisposes them to MS and that one or more environmental factors act as a trigger which leads to them developing MS. MS susceptibility is increased if a family member has MS. In general, a person’s risk of developing MS is 1 in 750, or 0.1%. This risk goes up to 2-3% if a first-degree relative (parent, sibling or child) has MS, and to 30% if a person has an identical twin with MS. Interestingly, the chances of developing MS for twins who are not identical is similar to that of other siblings.

MS can be diagnosed at almost any age, from childhood to the elder years. However, it’s more likely to occur in people ages 20 to 50. A recent study examined whether there is a pattern to birth month for people with multiple sclerosis. Results showed that spring babies are at a higher risk of developing MS. Specifically, people diagnosed with MS were 6.7% more likely to have been born in April, and 9% less likely to have been born in November.

Gender is also an important risk factor. Recent research suggests women are four times more likely to be diagnosed with MS. The sex hormones, estrogen, progesterone and testosterone, may be partly responsible for this gender gap. As discussed in our May 2018 newsletter, there’s growing evidence that the female hormones, estrogen and progesterone, can affect the nervous and immune systems. You’ll find an article in our June 2018 newsletter, detailing how testosterone, the primary male hormone, may also affect the immune response.
Geography can influence your chances of being diagnosed with MS. People who live farther from the equator (in more temperate climates) have a higher risk of developing MS than people living in hotter areas near the equator. Individuals living beyond the 40-degree mark north or south of the equator are far more likely to develop MS. This is especially true for people in North America, Europe, and southern Australia. Moving from one location to another seems to alter one’s MS susceptibility. If you move as a child (before the ages of 12 to 15), your risk of MS will likely change to match your new residence, whether you move from a low risk to a high risk area, or vice versa. For those who move later in life, the change in risk level may not be seen until in the next generation. This suggests that environmental factors in the place you live before puberty can influence your odds of getting MS.

Ethnicity plays an important role in whether an individual develops MS. It is more common in whites, particularly those with Northern European ancestry. Some groups seem to be at lower risk, for example people with African, Asian, Hispanic, and Native American ancestry. MS is very rare among other groups, including the Inuit (sometimes referred to as Eskimos), Australian Aborigines, and New Zealand Maoris.

One’s physique can influence their chances of developing MS. Evidence suggesting that obesity may contribute to the incidence of MS is growing. Scientists also believe obesity may worsen MS in people who already have the disease. In addition, taller women may be at greater risk for MS.

It’s a well-established fact that smoking increases the risk of lung cancer and heart disease. As Dr. Farren Briggs explains in our March 2018 newsletter, it’s also risk factor for MS. Smokers and ex-smokers are more likely to be diagnosed with MS than people who never smoked, and the more cigarettes you smoke the higher the risk. Individuals with MS who smoke also appear to be at a much greater chance of experiencing a more rapid progression of their disease.

Stress can worsen MS symptoms and research suggests that it can also increase the likelihood of developing MS. One study specifically studied the effect of extreme grief as a risk factor for MS. Results from this study found that parents of children who died were more likely than other parents to develop MS in the next decade. This likelihood doubled if the death was unexpected (such as an accident). Researchers are still trying to determine how much and what type of stress could lead to flare ups, disease progression, or even cause MS.
Preventing brain injuries in young people is important for many reasons. It now appears that preventing MS may be among those reasons. A recent study looked at associations between concussions during childhood or adolescence and development of MS later in life. Data from this study showed no link between concussion occurring from birth to age 10 and MS. However, concussion during adolescence (between the ages of 11 and 20) was associated with a higher risk of MS. In addition, individuals who’d had more than one concussion had an even higher chance of being diagnosed with MS than those with just one recorded concussion.

Having another autoimmune disease may also increase the likelihood developing MS, as autoimmune diseases tend to cluster. For example, if you have type 1 diabetes, autoimmune thyroid disease, or systemic lupus erythematosus (SLE), you may have a slightly higher risk of being diagnosed with MS, too.

While no particular diet or food has been shown to prevent MS, researchers continue to study the ways in which nutrition might affect disease risk. What you eat has a strong influence on the gut microbiome. As Dr. Farren Briggs explains in our September 2017 newsletter, this plays a strong role in MS, both at onset and on severity. Research also shows diet affects metabolic and inflammatory pathways. Inflammation is increased by high-calorie diets, which include foods that are low in fiber, and high in salt, sugar, fried food, red meat and animal fat. On the other hand, low-calorie diets that include vegetables, fruit, legumes, fish, and grains reduce inflammation and restore or maintain a healthy gut microbiome. Studies also confirm vitamin D is a key diet-related factor in the possible prevention of MS. Vitamin D is naturally present in fatty fish and is added to milk, some cereal products, and a few other foods. The most natural way to get vitamin D is through exposure to sunlight. Epidemiologists have determined that populations exposed to greater amounts of sunshine or ultraviolet radiation have lower rates of MS. A Swedish study recently found that a high consumption of coffee is associated with a lower risk of developing MS. In addition, Researchers have determined resveratrol (a compound in red wine) may exhibit anti-inflammatory effects in the brain and may also promote restoration of the myelin coating that surrounds nerve cells in mouse models. Another study showed that periodic cycles of a fasting-mimicking diet had beneficial effects in both mice and human participants with relapsing-remitting MS. Human subjects in this study reported improvements in their health and quality of life. Whether such a diet could help prevent MS is not known.
The hygiene hypothesis is based on the premise that our efforts to stay healthy by killing germs with surface sprays, antibacterial soaps and hand sanitizers has lead to an increase in the incidence of allergic and autoimmune disorders (such as MS). According to this theory, by cleaning and sanitizing ourselves and our environment, we’re no longer exposed to infections, parasites and microorganisms that would otherwise help to prime our immune system. Without this exposure, the immune system fails to develop fully and becomes overly sensitive, leading to increased risk of allergies and autoimmune diseases later in life. A recent Norwegian study determined, among other things, owning a cat during childhood was associated with a greatly reduced risk of developing MS in later life. The researchers concluded this was consistent with the hygiene hypothesis, since cats bring with them a number of microorganisms that may well help prime the immune system.

Researchers are considering the possibility that certain viruses and bacteria may be involved in the MS disease process, or even cause MS. Specifically, there is evidence that the development of MS may be due, at least in part, to exposure to the measles virus. If exposure occurs late in childhood or near adolescence, the risk of MS is increased. Investigators believe the human herpesvirus 6 (HHV-6) may be involved in the MS disease process. A recent study found that HHV-6 antibodies were associated with a higher risk of relapse and possibly with progressive courses of MS. Data from another study showed women with the common gut infection Helicobacter pylori (H. pylori) were less likely to develop MS than those without these bacteria. In addition, a 2003 study published in the Journal of the American Medical Association associates infection with Epstein-Barr virus (EBV) with an increased risk for MS.

Parasites may also play a role in the development of MS by regulating the immune system and reducing its responses. Studies show MS is less frequent in people infected with worm-like parasites called helminths. Furthermore, parasitic infections provide protection against the disease in mouse models. There have been several small studies looking at whether deliberately exposing people with MS to parasitic worms can reduce their levels of inflammation and reduce their MS disease activity. More research is needed to fully understand this new approach to immune therapy.

It’s important to mention what scientists have ruled out as MS risk factors. At one point, people believed that allergies might cause MS. Allergies are common in the general population and can occur in people with MS. However, there is no scientific evidence that MS is triggered by a reaction to a specific environmental allergen. There is also no scientific evidence to support claims that artificial sweeteners (such as aspartame) increase one's risk for developing MS. Some years ago, canine distemper (a virus carried by dogs) was proposed as a cause of MS, but research has since proven this to be incorrect. There are no data to support the belief that heavy metal exposure, such as mercury, lead or manganese, causes MS. Although poisoning with heavy metals can damage the nervous system and produce symptoms
such as tremor and weakness, both the process and the symptoms are different from those associated with MS.

The ACP Repository is an unparalleled resource for studies aimed at understanding the causes and mechanisms of MS. In addition to valuable blood samples from people with MS and healthy controls, it also contains a comprehensive set of related data. According to epidemiologist, Dr. Farren Briggs, “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.”

Cannabis and MS – the “High”-lights

The Food and Drug Administration (FDA) has approved many treatments for MS to help modify the disease course, treat relapses and manage symptoms, but none are completely effective. Many people with MS continue to experience flares, disease progression, and ongoing symptoms. As discussed in our August 2017 newsletter, some turn to alternative medicine to manage their symptoms and increase their quality of life, most often in combination with their prescribed MS treatments. One such treatment is cannabis, or marijuana. Cannabis is a tall Asian herb. The leaves and flowers of the mature plant are covered with trichomes (tiny glands) of oil. This oil contains chemical compounds that, when consumed, can cause physical and psychological effects. Cannabis can be taken via inhalation (smoked plant or vaporized extracts), orally (capsules, extracts, or “edibles”), or topically (lotions).

There are many types of chemical compounds in cannabis. Flavonoids are a large family of compounds found in most fruits and vegetables, in large part responsible for their vivid colors. They are important because they have been shown to have beneficial anti-inflammatory and antioxidant effects. Terpenoids (or terpenes) are aromatic chemicals responsible for marijuana’s unique smell. Cannabinoids are the chemical compounds that, when consumed, bind to cannabinoid receptors in the human body and alter nerve transmission in the brain (resulting in marijuana’s psychological effects).
The two major cannabinoids in cannabis that have been studied are tetrahydrocannabinol (THC) and cannabidiol (CBD). THC is thought to cause most of the psychological effects of cannabis. CBD has significant medical benefits, but does not make people feel “stoned” and can actually counteract the psychological effects of THC. There are many different strains of cannabis that have different concentrations and proportions of THC and CBD. It’s important to note that the appropriate dose of cannabinoids for different medical conditions is not known. In addition, production of cannabis products sold at dispensaries is not standardized. Products can vary in potency, and it can be unclear exactly how potential contaminants (such as herbicides or pesticides) are removed from the final product.

It is becoming more common for people with MS to use cannabis to try to alleviate their symptoms. A survey of people with MS published in 2017 found that 47% of respondents have considered using cannabis to treat their MS symptoms, 26% have used cannabis for their MS symptoms, 20% have spoken with their physician about using cannabis, and 16% are currently using cannabis. Ninety-one percent think marijuana should be legal in some form. It is important for people with MS and their providers to understand the available evidence surrounding cannabis treatment and to work together to make the choices that are right for them.

There have been numerous studies conducted to evaluate the therapeutic effectiveness of cannabinoids on MS-related symptoms. The CAMS (Cannabinoids in MS) study was the first large-scale study to evaluate this. In this study, 630 people with MS from 33 centers in the United Kingdom (UK) were assigned to receive a cannabis product or placebo twice daily for 15 weeks. Those taking cannabis reported significantly greater improvements in spasticity, spasms, and sleep compared to those taking placebo. There were no significant changes in tremor or bladder symptoms in any of the groups. More recently and also conducted in the UK, the MUSEC (MS and Extract of Cannabis) trial looked at patients’ perceptions of changes in muscle stiffness. In this study, 279 people with MS took either a cannabis product or placebo for 12 weeks. Those taking cannabis had almost twice as much relief from muscle stiffness as those taking placebo and they also had improvements in spasms and sleep. Pain is a common symptom of MS. Most MS-related pain is central neuropathic pain (pain caused from damage to the central nervous system) or pain from spasms. Another study showed cannabis-based treatment effective in reducing central pain in people with MS.

Botanical cannabis preparations (those obtained from the plant) have been legalized in many states for medical use and for recreational use in a smaller number of states. The laws governing the growers, dispensaries and prescribing of botanical products vary from state to state and are subject to change. For up-to-date information on state laws, it is best to check with the individual state government or the non-profit organization Americans for Safe Access website.
Although botanical cannabis has been legalized for medical and/or recreational use in a number of states, its use remains prohibited by federal laws. The Controlled Substances Act of 1970 places drugs into one of five categories (schedules I – V), based on their perceived medical benefit and potential for abuse. Cannabis is a Schedule I category drug, which is considered to be the most dangerous category. However, in 2014 Congress passed the Rohrabacher–Farr Amendment, which prevents the government from spending federal funds to prosecute cannabis-related activities if they are permitted under state-specific medical marijuana laws. It’s important to note that this amendment does not change the federal legal status of cannabis, and it must be renewed every year in order to remain in effect. Interestingly, in June 2018, the FDA approved the first plant-derived cannabis drug, Epidiolex, for treatment of two rare forms of epilepsy (Lennox-Gastaut syndrome and Dravet syndrome). This is in direct conflict with existing federal laws and there is much controversy surrounding whether or not cannabis should be downgraded to a Schedule II or III drug under the Controlled Substances Act.

To date, the FDA has approved two synthetic forms of marijuana for medical use, dronabinol (Marinol) and nabilone (Cesamet). Both drugs are approved for treating chemotherapy-related nausea and vomiting that does not get better with standard treatment. Dronabinol is also approved for people with AIDS who have loss of appetite with weight loss. At this time, neither drug is approved for other uses. Nabiximols (Sativex), a cannabis extract mouth spray, is approved for treatment of MS-related spasticity in Canada, New Zealand, and several European countries, however it is not currently FDA-approved and is therefore not currently available in the U.S. Produced by the Institute for Clinical Research in Berlin, Germany, Cannador is a natural cannabis extract that has been used exclusively in research studies in Europe.

There are a number of challenges in advancing cannabis research in the US. In addition to obtaining funding for their studies, researchers must file an Investigational New Drug (IND) application with the FDA, obtain a license from the US Drug Enforcement Administration (DEA) to conduct research with Schedule I drugs, and obtain cannabis for the study. When botanical cannabis is investigated, it must come from the University of Mississippi Marijuana Research Facility. The University of Mississippi has a contract with the federal government to grow cannabis for research. This marijuana may have been stored frozen for years (which may affect its quality and potency), and doesn’t take into consideration other strains or hybrids that patients may encounter. These obstacles can make conducting these studies more time-consuming and challenging than other investigations.

Cannabis can have a range of adverse effects. These may vary depending on the product and the individual. Recent research demonstrates cannabis can worsen cognitive function in patients with MS. Other side effects may include psychosis, tolerance and dependence, an increased risk for cardiovascular disease, as well as anxiety, nausea, vomiting, dry mouth, dry eyes, sedation, increased appetite, headache, as well as impaired balance and coordination. In addition, cannabis may interact with a person’s prescription and non-prescription medications. There is
conflicting evidence regarding whether or not smoking cannabis increases the risk of lung cancer. The long-term safety of marijuana use for MS symptom management is not yet known.

There are many open questions regarding cannabis use, including optimal strains, frequency of use, risks of long-term use, and which symptoms it effectively treats. iConquerMS™ was developed to engage people with MS to drive and shape research and to fuel research on topics, like cannabis, of great interest to people living with the disease. If you haven't already done so, please consider joining. With your participation and support, we can work together to find the answers to these, and many other important questions.

Meet Our Mighty Team

The Accelerated Cure Project is a small organization making a big impact toward curing MS worldwide. Our dynamic initiatives facilitate MS research and encourage collaboration between investigators. They engage people with MS to contribute valuable data and health information, and enable people with MS to steer research toward relevant topics. You may think it would require a large staff to accomplish so much. In fact, the ACP team is comprised of a small group of hard working people with diverse backgrounds. This month we would like to introduce you to our team.

The ACP team (left to right): Lindsey Santiago, Jan Weaver, David Gwynne, Sara Loud, Robert McBurney, and Hollie Schmidt
Robert McBurney  
*President and Chief Executive Officer (CEO)*

Robert has been at the helm of ACP for over 7 years. He works closely with the rest of the team to develop and implement the strategic directions of both ACP and iConquerMS. He plays a leading role in interactions with MS advocacy organizations and institutions that support MS research, representatives of healthcare companies and the research community, and people who are interested in supporting ACP’s work. Robert studied chemistry and physiology as an undergraduate, and earned a PhD in neuroscience (biophysics). He did neuroscience research for a number of years, after which he joined a biotech company that was discovering and developing medicines to limit brain damage in stroke and head injury, and to repair damage to the nervous system in MS. This was his first company experience in the biotech industry. Over the next 25 years, before joining ACP, Robert was Chief Scientist or CEO of a number of companies, some of which he co-founded with colleagues. A professional recruiter approached Robert in 2011, when ACP was looking for a new President and CEO. In his words, “I was very excited about the prospect of joining an organization that was committed to open science and a very different way of accelerating MS research.” Robert doesn’t have a personal family connection with MS, but knows many people who have MS. When asked what he enjoys most about working for ACP, Robert states, “We are a small but “mighty team” (a term once used by the CEO of the National MS Society to describe ACP). We take on big challenges and achieve substantial results and progress. Our 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 are an organization that depends on great collaborations to generate the research results that lead to improved health, healthcare and quality of life for people affected by MS.” Outside of work, Robert enjoys family activities (especially with his granddaughter), food and wine, outdoor activities (especially on or in the sea), golf, music, working on home repairs/improvements, and thinking about “stuff.”

Sara Loud  
*Chief Operating Officer (COO)*

Sara has been a leader at ACP since 2005. Initially, as Repository Director, she played a key role in building the ACP Repository. Over the years she has taken on more and more responsibility. As COO, she’s now responsible for making sure that “everything” gets done – from ensuring that our programs are delivering what’s needed to the MS stakeholders we serve, to fundraising, staff and volunteer management, accounting, etc. Sara studied electrical engineering in college and graduate school and worked as an electrical engineer (and later a “project and people” manager) for many years in high tech. She was never fully satisfied as an engineer, and wanted use her skill set for something more meaningful. So, she returned to school to earn an MBA with a focus on Social Entrepreneurship, after which she decided to move from the high tech to the nonprofit world. Sara learned about ACP on an Internet job board many years ago. Sara didn’t have a personal connection with MS until she started working for ACP. Over the years she’s developed a personal connection with ACP’s community of people affected by MS. When asked what she enjoys most about working for ACP, Sara states, “Do I have to pick just one thing? I love working really hard at delivering really important and novel resources to the MS community. I love the small but mighty team we’ve
built and the commitment we share to doing great work with meaningful impact. I love knowing that what I’m working on is really and truly accelerating research, and makes it better research thanks to the people-centered nature of our work.” Outside of work, Sara loves spending time with her husband, Jim, and their twelve-year old daughter, Charlotte. They have a small beach house in Maine that, in Sara’s words, is a “fixer upper – more fixer than upper”, so they spend time in the spring, summer and fall balancing walks on the beach with much hammering and painting. Sara also loves to volunteer. For the last few years she’s been a volunteer case reviewer for the Department of Children and Families. As such, she reviews the details of cases involving children in foster care to ensure that the people involved in the case are doing all they can to drive toward the best possible outcome.

**Hollie Schmidt**  
*VP of Scientific Operations*

Hollie has been instrumental in planning and executing ACP’s scientific activities since its inception. As co-chair of the iConquerMS Research Committee, she enjoys working with people with MS, researchers, healthcare providers, research funders and others to bring new studies and research activities into being. Before ACP, Hollie had a varied career. She worked in Design for Environment programs at a major industrial company, co-founded a computer software company and worked in public policy consulting. Hollie learned about ACP through her friend, ACP’s founder, who decided to start an MS nonprofit and asked if she would like to help. In Hollie’s words, “Little did I know it would lead me on a journey that has lasted 17 years so far! I didn’t have a personal connection with MS before my friend (ACP’s founder) was diagnosed, but since then I’ve learned about a few additional friends who have been diagnosed with MS. And, I have a personal connection with many people I’ve gotten to know well through ACP.” When asked what she enjoys most about working for ACP, Hollie states, “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!” Outside of work, Hollie enjoys playing games and solving puzzles, singing in a choir, going on road trips and hosting parties. Hollie also shares, “I’m a huge animal lover and at one point had 7 pets simultaneously (4 cats, 2 toads and 1 dog). I would love to add goats and/or snakes someday!”

**David Gwynne**  
*Alliances and Collaborations*

David has overseen outreach to scientists in industry and academia for the Repository, as well as data and business development for iConquerMS for almost 3 years. David’s background is in molecular genetics research, having led a number of drug discovery teams, as well as business development in biotechnology. Two of David’s good friends have MS, which brings the disease closer to home. He was introduced to ACP through his long-term friendship with ACP’s CEO, Robert McBurney. When asked what he enjoys most about working for ACP, David states, “I enjoy the science and the business challenge as well as the opportunity to interact with people living with MS.” With regards to ACP’s mission, “The ‘iConquer’ goal, underpinned by a commitment to the science of MS and people living with MS is especially meaningful.” Outside of work, David enjoys boating and “cottage life” in Canada.
Lindsey Santiago  
*Development Associate*

Lindsey wears many hats at ACP. Her fundamental roles include helping with the monthly newsletter, third party fundraisers, website updates, iConquerMS, as well as daily reporting and operations. In college, Lindsey studied business, with a concentration in marketing and entrepreneurship. She focused on online and digital advertising and marketing until joining ACP, at which time she moved from the for-profit to the nonprofit sector. Lindsey was diagnosed with MS in 2010 and learned about ACP from her neurologist. She’s participated in many of ACP's initiatives since then, including the Repository and iConquerMS. She shares, “When I first learned about ACP, I joined their young professionals group, and I became involved with different fundraising activities. I started volunteering at ACP when a position opened up. I applied, and the rest is history!” When asked what she enjoys most about working for ACP, Lindsey states, “I think the number of initiatives and collaborations we can be a part of is amazing with such a small team! I enjoy being able to do something to help research toward hopefully discovering a cure one day. I also enjoy the passion of people in the iConquerMS network. It amazes me that we can send out a survey asking a question, and within 24 hours have hundreds of people participate and answer because they’re just as passionate to help and to find a cure!” Lindsey also shares, “The idea that a cure is tangible, and might be in the data we currently have is so important. We just need to share it and have others share what they discover in order to have ideas multiply and be successful in figuring out the answers we are looking for.” When Lindsey is not at work, she is taking care of her almost 2 and a half year old son. She enjoys spending time with family and friends, whether it’s going out to dinner, watching a sports event on TV, or playing outside blowing bubbles!

Jan Weaver  
*Operations Manager*

Jan has been helping to advance ACP’s mission in various capacities since 2006. Currently she works part time and enjoys managing ACP’s communications (the newsletter), as well as helping with data requests from the Repository. Jan started her career in basic research, working as a laboratory technician in both the academic and pharmaceutical settings. After taking time to raise her family, Jan returned to work and transitioned from basic to clinical research, working as a clinical research coordinator. Jan first learned about ACP through her role as research coordinator for the ACP Repository at UMass Medical School. In Jan’s words, “I learned about MS through the hundreds of amazing people I enrolled in the Repository. I was touched by their stories and, to this day, am inspired by their amazing spirit.” When asked what she enjoys most about working for ACP, Jan states, “It’s an organization with a heart, and a cause that I believe in. I love working with a team of people that really care, about each other and about advancing the work that we do. Since I was first introduced to ACP, I’ve never viewed my work as a job, rather a mission to make a difference for the wonderful people I’ve met who live with MS.” Outside of work, Jan enjoys time with her family, relaxing with her needlepoint, puttering in her gardens and activities with her 5 Leonbergers. This past summer, Jan ventured into the world of dog breeding and enjoyed raising her first litter of 10 Leonberger puppies.
Repository Spotlight – Dr. Bob Axtell, Oklahoma Medical Research Foundation

When ACP provides Repository samples and clinical/phenotype data to researchers, we stipulate that their results must be returned to ACP, where they are available as an open resource for further study by other scientists. ACP has received several sets of returned research data from scientists who have completed their studies. One such researcher is Dr. Bob Axtell at the Oklahoma Medical Research Foundation. Dr. Axtell analyzed a broad range of different sample types from people with Neuromyelitis optica (NMO), a neuroinflammatory disorder that affects optic nerves and the spinal cord. Dr. Axtell examined different samples in order to get a comprehensive perspective on the genetic and biological basis of disease. These samples include DNA (to understand genetic linkages to disease), RNA (to examine how genes are expressed in disease), and blood plasma (to examine the changes in the profiles of cytokines, molecules that regulate the immune response). In addition, Dr. Axtell studied whole immune cells from blood to profile how different classes of immune cells (T- and B-cell subsets) change during disease. Dr. Axtell’s data, and other returned data sets, enrich the ACP Repository as a resource to advance and accelerate research into demyelinating diseases.

iConquerMS™ Spotlight – REAL MS

In the summer of 2016, the iConquerMS initiative launched REAL MS™ (Research Engagement About Life with MS), a longitudinal study of MS during which participants periodically provide information about their experience with MS through completing surveys. This month, a fifth round of REAL MS surveys were released through the iConquerMS portal. The information collected through these surveys will play a pivotal role in helping scientists and clinicians gain a better understanding of the health and quality of life over time for people with MS. Based on the premise that “Your Health Data Has Power”, this study is just one of the many ways iConquerMS is facilitating and accelerating research on topics of importance to people affected by MS. Please consider joining iConquerMS. Every piece of data expands the pool of information that researchers can draw from. Your voice matters!