

# Accelerated Cure Project for MS

December  
2018



*Accelerating research towards a  
cure for multiple sclerosis*

## A Look Back – Newsletter Highlights

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

2018

- **MS caregivers are a priceless gift.** Their [support and care](#) enable those living with MS to live the fullest life possible. Their unique perspective as the closest and most constant observer of the person living with MS has the potential to [transform](#) the research process. Providing round the clock care can be exhausting. In our February and November issues, we explored some [resources](#) that can help make this important job easier.
- **The only way MS research will benefit all is if a diversity of people participate.** The MS Minority Research Engagement Partnership Network is working hard to understand the barriers to [minority participation in research](#) and to overcome them. Read more about the work the Network is doing to help solve this problem.
- **How can clinicians and researchers fully understand the true impact of MS?** By collecting information directly from those who live with the disease! There is growing awareness of the importance of [Patient Reported Outcomes](#) in healthcare decision-making and for collecting comprehensive data for research. iConquerMS is on the pulse of this new trend, ensuring the voice of the MS community is heard!
- **Is stem cell therapy the MS treatment of the future?** [Stem cell research](#) holds tremendous promise for medical treatments, but scientists still have much to learn about how they work in the body and their capacity for healing.

- **Do you ever wonder why MS affects men and women differently?** There is mounting evidence that [testosterone](#), [estrogen and progesterone](#) affect not only the reproductive system, but also impact the nervous and immune systems.
- **Are you curious if the risk of developing MS can be influenced?** It is generally agreed that a variety of [factors](#) contribute to an individual developing MS. Some are genetic and therefore inherited, while others are environmental and can be controlled.
- **Have you considered trying cannabis to relieve your MS symptoms?** Research shows [marijuana](#) is effective in relieving spasticity, spasms, sleep, and in some cases, pain. However, there is still much controversy surrounding this alternative treatment.
- **Interested in what's happening in MS research?** Dr. Farren Briggs' articles provide our readers with relevant information on [trending topics](#) in MS research.
- **Would you enjoy a message of hope and inspiration?** This year we brought you interviews with four remarkable individuals living with MS who continually look on the bright side and work hard to make a difference for others in the MS community – [Richard Cohen](#), [David Bexfield](#), [Marc Stecker](#), and [Karen Jackson](#).
- **We appreciate our volunteers!** Whether they are helping with preparing mailings, [fundraising](#), or [contributing in some other way](#), we are grateful to each of our volunteers for their hard work and dedication on our behalf.

Caregiving is challenging work in many respects, physically, emotionally and financially. Providing care to a person with MS requires the person with the disease and the person providing support to be a team, working together. In February we featured [care partnerships](#), as well as some valuable resources that are available for both members of this important relationship. We also covered how [assistance dogs](#) can help with the completion of daily tasks and emotional support.

Caregiving is exhausting work, causing some to burn themselves out. In November, we explored the topic of [caregiver burden](#), and ways to help make this important job easier. Caregivers, in general, have a lot to offer toward advancing clinical research. Their knowledge of side effects, as well as physical or cognitive changes, and how these affect functioning and quality of life is

relevant and vitally important to consider at every step of the research process. Caring for a loved one with a long-term illness is a 24/7 job that can span decades. Those providing support are often so focused on their partner's needs they may not have time, or think to take care of their own. Families living with chronic disease cannot afford to have both the patient and caregiver sick at the same time. It's imperative for researchers to study caregiver health and burden, as well as coping mechanisms and strategies. In November, we stressed the [importance](#) of caregiver inclusion in research, as well as caregiver-focused research.



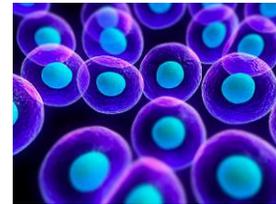
It's a known fact that people of different races and ethnicities can have varied responses to the same medicine. Diversity in clinical trials is key to ensuring that new discoveries and treatments are relevant to everyone. Less than 10 percent of subjects enrolled in clinical trials today are minorities.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

## PROs

- ✓ Health-related quality of life (HRQOL)
- ✓ Symptoms
- ✓ Function
- ✓ Satisfaction with care or symptoms
- ✓ Adherence to prescribed medications or other therapy
- ✓ Perceived value of treatment

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

Of the more than 200 types of cells in the human body, stem cells are the most versatile. They can replicate and develop into every organ and tissue in the body. Stem cell therapy is a treatment that uses stem cells, or cells that come from stem cells, to replace or to repair a patient's cells or tissues that are damaged. In April, we featured these [pioneering treatments](#), their potential benefits, and limitations. Also highlighted in April are the experience and perspective of two individuals, both of whom received stem cell therapy for their MS and are working to spread the message of hope to others living with MS, [Richard Cohen](#) and [David Bexfield](#).



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

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



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

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



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

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

