



*Accelerating research towards a  
cure for multiple sclerosis*

## A Look Back – Highlights from 2017

2017 has been an exciting and productive year at ACP.

- **Looking to participate in research in a novel way?** Our people-powered research network, iConquerMS™ has achieved new enrollment milestones and its members have contributed in meaningful ways to a number of research activities. Some have helped design research studies and products, while others have participated in research studies. Many have contributed valuable suggestions for the future direction of MS research.
- **Many of our readers have participated in the ACP Repository. Wondering if your samples are having an impact? They are!** ACP Repository samples continue to advance MS research around the globe. Research accelerated by ACP Repository samples and data has resulted in new diagnostic capabilities for, insight into the mechanism of and potential new treatments for MS.
- **Interested in what's happening in MS research?** Dr. Farren Briggs' monthly column is a new addition to our newsletter this year. Through it he provides our readers with relevant information on trending topics in MS research.

# 2017

- **Wonder how we get it all done with our small but dedicated team?**

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.

The ACP newsletter is one of the vehicles through which we keep you informed about new findings in MS research, the latest news from ACP, and our volunteers' contributions. As the year draws to a close, we'd like to share some of our highlights from 2017.

In 2017, [iConquerMS](#), our people-powered research network, grew to a network of over 4,200 members who want to engage in, learn about, and influence MS research. In the summer of 2016, iConquerMS 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 surveys. In August 2017, a third round of REAL MS surveys were released through the iConquer MS 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.

iConquerMS members were recently invited to be part of a research study on the topic of health insurance, led by Dr. Deborah Miller of the Cleveland Clinic. In May, Dr. Miller and her colleagues presented [two posters](#) at the CMSC meeting in New Orleans, LA. Data from this study showed that most of the study participants reporting having



health insurance, but over half of them were concerned about losing this insurance if their employment situation changed.

Also, fewer than half of the participants had disability or long-term care insurance that would provide support if they became disabled. The study team is now working on additional analyses and publications, and the National MS Society will be using their results in its public policy and educational efforts.

Also in May, iConquerMS members were invited to take a [survey](#) on research participation and perceptions among people with MS. Data collected from this survey showed that racial and ethnic minority groups are not fully represented in clinical trials

in general, including iConquerMS and the ACP Repository. ACP's [MS Minority Research Engagement Partnership Network](#) is working to study the reasons behind this imbalance. Survey results will help us understand which factors are most important to focus on in research-related outreach efforts.

The impact of iConquerMS reaches beyond multiple sclerosis. It is part of a national enterprise called [PCORnet](#) that is organizing networks of people with many diseases. There are a total of 34 PCORnet partner networks that cover more than 150 conditions. When combined, this network has collected data from over 90 million Americans. ACP is proud to play a part in creating this extraordinary resource for scientific research!

ACP Repository samples played a key role in a number of groundbreaking discoveries this year. ACP Repository samples contributed to the development of a new [blood-based diagnostic test](#) for MS. This new technology could reduce the time for diagnosis and allow patients to be treated before significant tissue damage occurs. ACP samples were also used in research leading to the generation of an [antibody](#) that could be the first treatment to directly target a potential cause of MS. This antibody is currently being studied in clinical trials. With a good safety and efficacy profile, the treatment may have a therapeutic effect on both relapsing remitting and progressive forms of MS. In addition, the discovery of [possible biomarkers](#) for MS was enabled by ACP Repository samples. This new information may help physicians to diagnose MS, and provide new insight into a mechanism that could determine the transition from relapsing remitting MS to secondary progressive MS. This may lead to faster, more precise diagnoses, as well as to future treatments for MS, including treatments for progressive forms of the disease.



Dr. Farren Briggs kept us up to date on other developments in MS research in his column over the past year. Farren's articles told us about [new biological mechanisms](#) which may shed light on what goes wrong in the immune system of people with MS, as well as those predisposing individuals to contract MS. Dr. Briggs also brought us exciting, new information in the search for [biomarkers for MS](#). Farren's column was an interesting read for those looking for information on other MS-related topics, such as the role of the [microbiome](#) and the [impact of exercise](#) in MS. Also included were

articles explaining when [MS symptoms actually start](#) in the natural progression of the disease, and the benefit of [Vitamin D supplementation](#). We are grateful to Dr. Briggs for his time and expertise over the last year and look forward to reading more in 2018!

Volunteers make a huge difference in ACP's success. We strive for each of our volunteers to contribute in a way that they find rewarding and fun. Some of our volunteers enjoy helping us with fundraising. In particular, Kemp Jaycox held his annual [Walk to Cure MS](#) and Marion Carroll held her 15<sup>th</sup> [Music to Cure MS](#) event in October. In the spring, sisters Nancy and Judy Medeiros held their annual [Sports Scholarship Benefit](#) in memory of their brother. Patrick and Erin Curley [kayaked](#) in the Essex River Race to benefit ACP, and Rick Szczepanski raised funds for ACP through the Mary J. Szczepanski ["Never Give Up" MS Scholarship Foundation](#). Throughout the year, Freda Warrington, author of ["Listen to the Light: Stories of Interruptions, Intersections and Insights"](#) has generously donated the proceeds from sales of her book to ACP. As described in [Volunteers Make a Difference](#), some of our volunteers like to help with administrative tasks and other projects in the office, while others prefer to work remotely. We are grateful to each of them for lending us their time and talents. Whether they are helping with fundraising, preparing mailings or contributing in some other way, their efforts enable us to continue our work to improve diagnosis, optimize treatment and find a cure for MS.



Working with our partners, we've made significant progress in our mission in the last year. iConquerMS has grown and its members have engaged in and contributed ideas to the future course of MS research. Samples from the Repository have enabled groundbreaking discoveries worldwide. We're grateful for the generosity of our volunteers, who have donated countless hours to help us do this work. We're thankful to Dr. Farren Briggs for keeping us abreast of new findings relating to MS in the literature. We look forward to new possibilities in the upcoming year. Stay tuned, and look for updates in future newsletters!

