

Accelerated Cure Project for MS

December 2017



Accelerating research towards a cure for multiple sclerosis

We, at ACP, are blessed to work with many partners in our mission. Together we've made significant progress toward our goals over the past year. iConquerMS™ network members and ACP Repository participants have provided a wealth of information and samples for MS research. Both have played a key role in gaining insights into the cause and treatment of MS, and improving the quality of life for people with MS. Dr. Farren Briggs has kept us abreast of current topics and new developments in MS research through his monthly column. Volunteers have generously helped us with many of our daily tasks and longer-term projects. Our first article summarizes some of ACP's milestones and accomplishments from the last year.

In the second article, Dr. Farren Briggs discusses the relationship between MS and diets. He also touches upon how different types of social interaction can effect our emotional health.

Our volunteers come from a variety of backgrounds and help us in many different ways. Some give of their time in the office, while others work remotely. The [November newsletter](#) highlighted two individuals that enjoy hosting annual fundraising events to benefit ACP. This month we'd like to introduce you to others who have answered the call to volunteer and tell you about the projects they are working on.

The iConquerMS initiative is truly unique in that it is governed by a majority of people with MS. The Governing Board, Engagement committee and Research committee each have a pivotal role in the success of iConquerMS. In September, we gathered the members of the iConquerMS governance along with other stakeholders in MS at our annual Leadership Summit, to envision the future of iConquerMS and the impact it can have on the lives, health, and well-being of people affected by MS. This month's newsletter includes some highlights of this amazing gathering!

With the season of giving upon us, we would like to express our heartfelt thanks for the many ways that our partners, donors and volunteers have given of their time, talents and resources. Your contributions make a huge difference in ACP's success. We hope you enjoy our

newsletter and encourage you to share it with anyone you think may be interested in learning more about ACP. We wish you and your family a happy holiday season and wonderful new year.

The Accelerated Cure Project Team

A Look Back – Highlights from 2017

2017 has been an exciting and productive year at ACP.

2017

- **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.
- **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 15th [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 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 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!



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Multiple Sclerosis – 'Tis the season for food, family, friends and frankincense

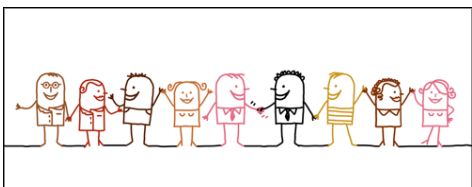
By Farren Briggs PhD, ScM

The weeks between Thanksgiving and the New Year mean many different things to each of us. But I think it's fair to say we all have a lot of "F"s on our minds: food, family, and friends, and for some of us frankincense. This December delivered on publications touching on all these festive themes.

This first study by Fitzgerald et al¹, published in *Neurology*, looked at the relationship between diet and disease severity in persons with MS (PwMS). It was a cross-sectional study – meaning both the 'exposure' (diet) and the 'outcome' (disease severity) were recorded at the same time. Data were collected on 7,639 PwMS using a detailed questionnaire, which was administered by the North American Research Committee on MS (NARCOMS) in 2015. There were 26 dietary questions which were used to determine the amount of the following foods in each diet: 1) fruits, vegetables, and legumes, 2) whole grains, 3) sugars from desserts and sweetened beverages, and 4) red and processed meats. The values were also combined into a single composite score of diet quality. There were some notable, but not surprising differences in the general characteristics of PwMS with the lowest versus the highest diet quality: those with the lower diet quality were more likely to have a higher body mass index, more likely to smoke cigarettes, less likely to participate in leisure physical activity, and of lower income compared to those with the highest diet quality. There



were no differences by age, gender, MS subtype, DMT use, race, onset age, and disease duration across the diet groups. The highest diet quality score included higher levels of fiber, calcium, whole grains, fruits, vegetables, and legumes, and lower levels of added sugar, sweetened beverages and red/processed meats. The authors compared disability levels between those with the lowest and highest diet quality score. Those with the best dietary scores were 25% less likely to have severe versus mild physical disability than those with the worst dietary scores. And it seems this effect was largely driven specifically by high levels of whole grains and dairy. Also those with the highest dietary scores had lower scores on a depression tool than those with the worst dietary scores. Lastly, the authors combined diet, with smoking status, body mass index, and physical activity levels to create a “healthy lifestyle” score – those with higher healthy lifestyle scores had a lower odds of reporting severe fatigue, depression, pain or cognitive impairment. All in all, this study suggests better diet does do a body and mind good, but I must acknowledge one limitation of this cross-sectional study design: we cannot establish temporality – thus, are those with better diets having better MS outcomes, or are those with better MS outcomes (because they are less disabled and less likely to be depressed) able to eat healthy and engage in less adverse behaviors? It’s the chicken and egg question – it’s not clear which came first. Nonetheless, this study was a well-done cross-sectional investigation from which many hypotheses can be generated.



Now during the holidays, we engage our families – both those we were born into and those we have chosen. For many of us, we interact with our various ‘families’ in-person, via e-mails, and on the multitude of online social

media platforms – and we intuitively understand that being *social* is good for us. But the question is: do in-person and online interactions have the same effect on emotional health? Sparling et al², published in *Quality of Life Research*, one such study using 508 PwMS from the NARCOMS registry and social participation survey. Again, this too was a cross-sectional study, and the authors were concerned with participation bias – whether the PwMS who decided to complete the social participation survey truly represents the general MS population – nonetheless, this is a concern for every epidemiologic study, and again these findings are hypothesis generating. The authors observed that in-person interactions with friends were associated with increased happiness, and decreased depression, anxiety and stress. There were no association between happiness, depression, anxiety, and stress with online-interactions once in-person interactions were accounted for. Even though we can’t state if it is a ‘causal’ association (again, the chicken and egg situation), it doesn’t hurt to make plans and catch-up to someone in-person.

The last study, by Stürner et al³, published in *Journal of Neurology, Neurosurgery, and Psychiatry*, gives an update on a clinical trial using frankincense extract and disease activity in RRMS. Frankincense is an aromatic resin (pictured right) extracted from hardy trees native to the Arabian Peninsula (Yemen, Oman) and northeastern Africa (Somalia). For millennia, frankincense has been used in non-Western medicine as an anti-inflammatory compound. This update was to report on the safety of frankincense extract in a small sample of 28 PwMS. Overall, the extract was well tolerated, however there was an increased in gastrointestinal events. The authors compared the number of MRI lesions at baseline to 8 months later while taking the extract. There were significant reductions in the number of new lesions, the total number of lesions, and the volume of the lesions at month 8. There was also a modest yet significant increase in total brain volume between baseline and month 8. The authors also assessed changes in the immune cell populations during this time, and there was no difference in the overall count of white blood cells, but there were significant changes in specific subsets – suggesting that the beneficial effect of the frankincense extract may be through immunomodulatory mechanisms. These results are intriguing and I will be following this clinical trial over the next many months at the following government website: <https://clinicaltrials.gov/show/NCT01450124> (FYI: all US clinical trials are registered on this site).



So, 'tis the season to be festive, but do eat well, connect with friends and family, and try not to spend all your gold.

1. <https://www.ncbi.nlm.nih.gov/pubmed/29212827>
2. <https://www.ncbi.nlm.nih.gov/pubmed/28702838>
3. <https://www.ncbi.nlm.nih.gov/pubmed/29248894>

Volunteers Make a Difference

Volunteers from all over the world help us with a wide variety of tasks each year. In our [November newsletter](#) we told you about two individuals who give of their time and talents to host third party fundraising events to benefit ACP. Some of our volunteers come in to the office to help with administrative tasks and other projects, while others work remotely. ACP recruits many of its volunteers through postings on [Volunteer Match](#), a network that connects volunteers with opportunities that match their skills in the nonprofit sector.



VolunteerMatch

We'd like to introduce you to some individuals that have answered the call to volunteer at ACP. They all have different backgrounds and interests, and volunteer their time and talents in different ways.

Corinne Rhode's most recent project was to review ACP's mailing list to ensure that it is accurate and up-to-date. Corinne worked in banking for 13 years and has since transitioned to photography, focusing mainly on travel and landscape photography. Corinne learned about ACP through Volunteer Match. ACP's posting caught her eye because she has friends with MS. Corinne shares, "I thought my skills were a good match to the posting and I thought I could add value to the organization." When asked about volunteering at ACP, "It's quite rewarding, knowing that I am helping out, and the people at the office have been so friendly and welcoming. It's enjoyable coming in for my weekly stint."

Betty Lapide helps by writing thank you notes to donors, packaging t-shirts and tote bags for people who complete their surveys on [iConquerMS™](#), organizing things in the office and "whatever else needs to be done." She is from a small town in western Pennsylvania, and moved to Boston after college. Betty was an elementary teacher, grades 4-7, for 38 years. She loves to bake, garden, play MahJongg, have lunch with friends and exercise. She learned about ACP while doing online research after she was diagnosed with MS in 2007. Betty states, "I want to do anything I can to help find a cure for MS." When asked about volunteering at ACP, "I love it! The people are extremely friendly and helpful, and I feel as if I'm a member of the staff! It's sort of like a family atmosphere there."

Christian Lazzari is currently helping us create a database of potential corporate donors and sources of funding in order to streamline the grant application search and submission process. He's currently a senior at Bentley University graduating in May 2018 with a major in

Corporate Finance and Accounting. Christian is currently applying for rotational finance programs at companies in NH and MA. Outside of academics and work, he is a huge Denver Broncos fan and loves to cook. Christian learned about ACP through Volunteer Match. Christian states, “I volunteer at ACP because I care about the work that’s being done. Finding better ways to treat and possibly cure MS would be amazing and I feel proud that I can help in any way possible.” When asked about volunteering at ACP, “Volunteering at ACP is very enjoyable because everyone is extremely friendly and welcoming. Also, coming in, I was able to sit down and figure out tasks that I could work on that I’d enjoy, which made it easy to quickly start contributing.”

David Hallan worked remotely to gather valuable information for ACP in the recent past. Utilizing various data extraction techniques, David compiled a list of social media outlets related to Multiple Sclerosis to potentially be used in ACP’s outreach efforts. He also gathered information on MS sample availability from a number of different biorepositories and compiled a detailed list comparing 40 organizations with available MS samples. David’s third project was to research diagnostic companies to determine whether or not they provided some form of MS or autoimmune testing. From this research, he compiled a detailed list of 95 companies with an MS or autoimmune connection. David has a research background in biophysics, and is currently a medical student at Penn State University College of Medicine. Previously he worked in the nuclear industry, and is a former full-time LDS missionary. David learned about ACP on [Google](#). When asked about volunteering for ACP, David states, “Everyone was so kind!”

It’s been a pleasure working with Corinne, Betty, Christian and David this year. We appreciate the contributions they, and many others, have made in support of our work. Their efforts make a big difference in ACP’s success. If you are interested in joining the ACP team as a volunteer, please visit [ACP’s post](#) on Volunteer Match for available volunteer opportunities, or feel free to contact us. We strive for each of our volunteers to contribute in a way that they find rewarding and fun. Do you have an idea for a project that would help us in our mission? We are open to your suggestions! In either case, contact Lindsey Santiago by phone (781) 487-0013, or by email lsantiago@acceleratedcure.org. We would love to hear from you!



Research, Powered by People Affected by MS

They say that two heads are better than one. If so, what then can five, ten, twenty, forty or more people accomplish together? Incredible things! All we have to do is look to the iConquerMS™ initiative to get a glimpse of what happens when you bring a large group of people together to think, build, create, and solve!

We've told you a bit about iConquerMS in [previous newsletters](#). One of the truly unique aspects of iConquerMS is that it is governed by a majority of people with MS. The initiative is guided by a governing board (responsible for the overall direction and sustainability of iConquerMS), an engagement committee (responsible for the activities associated with the recruitment and retention of the membership) and a research committee (responsible for overseeing the research approval process). The board and committees are populated with a committed and diverse group of people who bring research, business, legal, communications, marketing, and life experience to the table. A majority of these people have been diagnosed with MS and all members of the governance care deeply about accelerating research on topics that matter most to people with the disease.



The governing board and committees work together remotely through conference calls and emails to get the work done needed to change the world of MS research. Once a year, however, we gather in person at our annual Leadership Summit. All members of the governance are invited to attend and we also invite other stakeholders in the MS community -- friends, new and old to the initiative -- to gather with us. This year's summit was held in September in Boston, MA.¹

For two days, attendees at the Leadership Summit gathered together to envision the future direction of iConquerMS and discussed how to ensure the initiative is as impactful as possible. Guided by facilitator Ora Grodsky from [Just Works Consulting](#) and with lots of laughter, hard work, and camaraderie, the group worked to put in place a refreshed purpose and vision for the initiative, a set of guiding principles, and to begin to craft some possible strategic directions for the next 5 - 10 years.

¹ The 2017 iConquerMS Leadership Summit was made possible through funding by Biogen and Genzyme, a Sanofi company.

Forty people strong, the majority of whom are people living with MS, attendees came from near and far (Italy!), spanned ages, experiences, and prior knowledge of iConquerMS. Health care providers and researchers, representatives from industry and academia, people with MS and care partners, each brought their unique perspective to the discussions. All came ready, willing, and able to share their ideas, insights, and experiences to further shape iConquerMS into an endeavor that can and will change the role of the person with MS in research and lead to faster and more impactful research.

After introductions and ice-breakers, the group quickly got down to work refining the purpose and vision of the initiative. “What’s exciting and inspiring?” “What works and what doesn’t?” the team was asked to contemplate. Through spirited discussion and building off of each other’s ideas, the purpose and vision emerged:



Purpose: To improve health, healthcare, and quality of life for people affected by multiple sclerosis (MS) by connecting those with MS, care partners, clinicians, and researchers, and to work together to accelerate innovation, research, and the application of new knowledge.

Vision (5-10 year timeframe):

1. Improvements in health, healthcare, and quality of life of people affected by multiple sclerosis (MS) result from new ways of thinking, doing, and sharing, and are centered on the needs of people affected by MS.
2. iConquerMS™ is the community platform for people affected by MS to contribute in a vital and continually evolving manner to all activities - research, innovation, and quality improvement - that transform MS healthcare and improve the quality of life of people affected by MS.
3. The health of people affected by MS is the result of treatment and care decisions made jointly with their clinicians and other trusted people based on robust evidence about the benefits and harms of conventional medicines, alternative therapies and lifestyle changes, for individuals with particular characteristics.
4. The evidence comes from research planned and conducted by people affected by MS collaborating directly with researchers and other stakeholders who all are contributing to ensure that the evidence is rapidly disseminated to healthcare practice and to other settings that people affected by MS go to for credible information they need to manage their disease.
5. People affected by MS are routinely and consistently playing key roles alongside clinicians and other stakeholders in the design and oversight of an MS healthcare system that is continually improving and seeking to incorporate innovation and to identify and fill evidence gaps.



With this excellent work behind them and buoyed by the clarity of purpose and vision, the team retired to a nearby restaurant to relax, socialize, and build upon the excitement and enthusiasm of the day's work. All were up early the next morning (some might say too early!) to tackle the guiding principles -- words that will guide every action and interaction for the initiative. The guiding principles presented below are the result of work done at and after the Leadership Summit.

Guiding Principles:

1. Empowering people affected by MS People affected by MS have an important voice in guiding research to achieve better outcomes. iConquerMS, with its leadership rooted in the MS community, is committed to governance and guidance by people affected by MS.

2. Transparent and Trusting Relationships Researchers, healthcare providers, and people affected by MS rely on each other for transparency and honesty. iConquerMS holds itself to the same standards in all our relationships.

3. Good Stewardship The financial assets of the organization and the personal data in our care are protected and used in the best interest of people affected by MS. iConquerMS protects the privacy of our members through policy, process, and technology.

4. Sustained Community In our search for improved outcomes for people affected by MS, the greatest impact will occur with continued and sustained engagement of the MS Community.

5. High Quality Research We believe the most important research is meaningful and relevant to people affected by MS, addresses their needs, fills a gap in the research agenda, is actionable, and is conducted rigorously.

6. Inclusivity All people affected by MS are encouraged to participate in iConquerMS at the level of their choosing.

7. Transformational Collaboration In order for iConquerMS to be of greatest value, people affected by MS, researchers, healthcare providers, other MS advocacy organizations, and funders need to work in partnership, sharing information and experiences. iConquerMS is transforming MS research and care and provides value to all stakeholders.

Nearing the end of our time together, the team took up the challenging and invigorating task of envisioning possible future strategic directions for iConquerMS, the places we might focus to expand and increase our impact. Breaking up into small groups, each one focused on a different possibility, the groups grappled with questions like, “How would this strategic direction add value for people with MS, research community, clinicians, industry?”, “What would we be doing differently than we are doing today in order to advance down this path?”, “What resources might be needed?”, and “Who else needs to be involved with the initiative to make this happen?” Words like culture shift, community, advocacy, and research, research were overheard amidst the spirited debates, chatter and laughter. The Summit ended with the possible strategic direction explored and understood, pages and pages of brainstorming notes, and the promise of completion of the work with a smaller team post-Summit. The “Next Steps Committee” has actively taken up the discussion (back to phones and email) and are making great progress towards finalizing the strategic direction. Stay tuned!



And so after two days and much sharing, talking, listening, learning, and doing the Summit attendees traveled back to their homes with that hard-to-define mixture of exhaustion and exhilaration that comes from collaborating with others who are inspired to change the world for the better. The work since the Summit hasn't stopped, the enthusiasm hasn't waned. Interested in learning more about iConquerMS and getting involved in this novel initiative? Email Sara at sloud@acceleratedcure.org.

Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has. -- Margaret Mead

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