

Accelerated Cure Project for MS

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*Accelerating research towards a
cure for multiple sclerosis*

A Look Ahead – Transformational Collaborations

[iConquerMS™](#) was established to enable and accelerate MS research and other initiatives with the goal of improving the health, healthcare and quality of life of people affected by MS. The initiative does this by connecting those with MS, care partners, clinicians, and researchers, and encouraging them to work together to accelerate innovation, research, and the application of new knowledge. In less than 4 years the network has grown to over 4,700 registered members, almost 3,000 of which have contributed data about themselves and their experiences of living with MS as part of [REAL MS™](#) (Research Engagement About Life with MS). To date, iConquerMS has collaborated with researchers and organizations to enable and accelerate 11 research projects. We anticipate reaching new milestones in the New Year!

2019

In September, the iConquerMS governance and other stakeholders in the MS community gathered at our [Leadership Summit](#) to discuss the future direction of iConquerMS. The key focus of this year's meeting was "transformational collaborations." One might ask, what does this type of collaboration mean? In general terms, collaboration is defined as "the act of working with someone to produce or create something." Taking it one step further, transformational collaboration is focused on achieving a major change in the grand scheme in which all parties are involved and uses a novel process to achieve the desired outcome. Whereas those in a traditional collaboration may have varying degrees of involvement and differing priorities, all members of a transformational collaboration are equal partners. This type of collaboration rises above individual concerns and focuses on a shared priority. The stakeholders in a transformational collaboration may initially approach the collaboration with different priorities, incentives, or approaches. These differences are a contributing factor to

the transformational aspect of the relationship. These “unlikely partners” respect and recognize their differences, are willing to be flexible, and come to a shared understanding.

Representatives from many stakeholder groups attended ACP’s Leadership Summit in September (people with MS, care partners, industry, researchers and leadership from other MS organizations). Participants enjoyed stimulating dialogue throughout the meeting and agreed that patients are an underutilized hub of information in research. Participants with MS and their care partners overwhelmingly expressed they want to be heard and involved in their treatment plan. The challenge moving forward is focusing on ways to create collaborations that will transform MS research so the patient/caregiver voice is heard and prioritize benefits to people affected by MS. There is no road map for this difficult task. The iConquerMS governance and stakeholders in the MS community agreed that achieving this exciting new milestone in MS research will require approaching traditional methods from a different angle. We must bring divergent views to a common rally point and step out of our collective comfort zones.



Transformational collaborations for iConquerMS will bridge differences and reframe the research conversation and process, supporting a shared aspirational mission that forms relationships across cultures, unlocks greater value, and has more of an impact in 2019 and beyond. Summit attendees agreed that a “trusted voice” is the most impactful way of informing people about iConquerMS and encouraging them to participate. The “trusted voices” are the key influencers, such as leading MS organizations and individuals, most often in the digital space, who build communities and followers through the sharing of important and impactful information about MS. With the goal of increasing enrollment in iConquerMS, in order to more effectively impact MS research, we must increase the “trusted voices” that know about and share information about iConquerMS. With this being the key focus for 2019, iConquerMS leadership will reach out to support groups, MS organizations, and key influencers in a personalized way and relate the value of iConquerMS. Successful engagement will boost iConquerMS enrollment and build the research capacity of the network.



What might be possible if we built transformational collaborations? Those participating in this year’s conference enjoyed discussing their exciting potential from many viewpoints. From the caregiver perspective, it was agreed treating MS should include treating the caregiver. Transformative collaborations would involve a cultural shift in which an equal emphasis is put on the health and wellbeing of the care partner, in addition to the patient. The resulting paradigm would be one in which the goal of the first neurology visit would be to understand what the care partner **team** needs in order to manage MS and live with it (including health assessment of the care partner).



Age perceptions and restrictions affect people living with MS. Summit attendees wondered why clinical studies have age restrictions and often limit the participation of people with MS over the age of 60. As a result, these important data are missing. The consensus was that there need to be more clinical trials involving those on the upper end of the age spectrum, to better inform treatment decisions and lifestyle and wellness choices. Transformational collaborations through iConquerMS may be one way to get these studies done and broaden the knowledge base.

As we discussed in our [February 2018 newsletter](#), diversity and inclusion is key to ensuring medical research benefits all. Discussions at the Leadership Summit concluded information and resources could be delivered to underserved communities with the help of all MS organizations. Such efforts will increase minority enrollment in clinical trials and other research studies, including iConquerMS. Potential venues might include community centers, health fairs, libraries, or churches. The group agreed on the importance of transparency in all outreach efforts, ideally including personal stories of those living with MS.

Our current healthcare system was another hot topic of discussion at this year's Leadership Summit. Participants talked about how transformational collaborations might revolutionize the current concept to universal healthcare -- one that is high quality, accessible and affordable for all. All recognized the importance of getting started as such a change could take decades to achieve. The group was encouraged to think about demonstration projects that might facilitate the process. The importance of getting all stakeholders on board was emphasized, as was addressing the political climate, in order to affect such a change. Transformative collaborations could also bring healthcare into the home through [telemedicine](#) in the not too distant future. Leadership Summit attendees enthusiastically discussed including a survey about healthcare delivery options (including telemedicine) through iConquerMS in the coming year.



Another interesting topic at this year's Leadership Summit focused on nutrition and supplements. The group recognized the importance of studying the clinical outcomes of good nutrition and the beliefs surrounding it, as well as ways to provide a good diet in a different way (for example, Meals on Wheels or new meal kits). It was even suggested that a dietary component be added to clinical trials in the future. The group agreed that transformative collaborations would be instrumental in understanding the benefit of good nutrition in people with MS, as well as provide wider access to healthy food. Input from those living with MS, sponsors, healthcare practitioners, scientists, nutritionists and dieticians would ensure the effectiveness and applicability of these efforts.

To keep the momentum going, a "Next Steps Committee" (NSC) will work together over the next year to advance the work begun at the Summit on each of these areas of transformational collaboration. The NSC has actively taken up the discussion and is making great progress building on the work of the Summit.

Collaboration has been the cornerstone of ACP's work since its inception. In 2019 and beyond, ACP will focus on ways to create transformational collaborations for iConquerMS, ones that will transform MS research, provide value to all stakeholders, and prioritize benefits to people affected by MS. These partnerships will leverage all resources for the education and support of those affected by MS. They will evaluate existing programs and services to identify gaps, and involve those living with MS of all ages (including those outside the norm) to ensure everyone's needs are met. We look forward to an exciting and productive New Year! Stay tuned!

