

Accelerated Cure Project for MS

December 2017



Accelerating research towards a cure for multiple sclerosis

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.

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:



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

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, research were overheard amidst the spirited debates, chatter and laughter. The Summit ended with the possible strategic directions 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 is making great progress towards finalizing the possible strategic directions. 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