

Accelerated Cure Project for MS

October
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*Accelerating research towards a
cure for multiple sclerosis*

iConquerMS: Making Transformational Collaborations Possible

As described in our [June 2017 newsletter](#), iConquerMS™ empowers people affected by MS to drive MS research and accelerate efforts toward improving treatments and finding a cure for MS. This initiative is overseen 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 comprised of a committed and diverse group of people, the majority of whom live with MS, who care deeply about accelerating research on topics that matter most to people living with the disease.

For most of the year, the governing board and committees work together remotely through conference calls and emails. However, each year the

Leadership Summit provides an opportunity for members of the governance, along with other stakeholders in the MS community (health care providers and researchers, representatives from industry and academia, people with MS and care partners) to gather in person to envision the future direction of iConquerMS and discuss how to ensure the initiative is as impactful as possible. Fifty-six people gathered at this year's Summit, held September 15-16 in Boston, MA. Ora Grodsky from [Just Works Consulting](#) facilitated the Summit again this year. The group focused on ways to create collaborations that will transform MS research, provide value to all stakeholders, and prioritize benefits to people affected by MS. Attendees aspired to learn new ways to touch those living with MS, improve their quality of life, and

2018 Leadership Summit

spread the message of hope. Discussions resulted in a shared understanding of the needs, priorities and contributions of the various stakeholder groups, as well as strengths we can build on going forward.



After introductions and icebreakers, the group quickly got down to work building on the purpose, vision and guiding principles from last year's [Leadership Summit](#).

After reviewing these key points, discussions turned to the strategic direction of iConquerMS. The group was asked to contemplate “What are our directions and what have we accomplished?” Through enthusiastic discussion and building off of each other’s ideas, the following strategic directions were solidified:

Strategic Direction of iConquerMS – Foster Patient-centered Research

Promote a patient-centered model for research on topics that matter most to people affected by MS, which involves the direct contributions of the MS community in design, implementation and dissemination.

Engage with researchers to familiarize them with iConquerMS research resources, emphasize the benefits of patient-centered research, and invite collaboration.

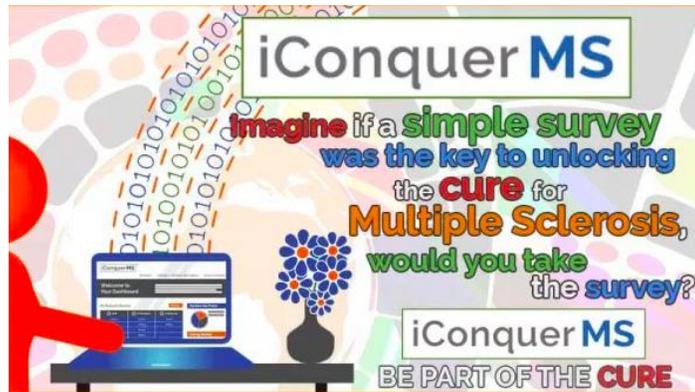
Develop partnerships among researchers, providers and people affected by MS in order to promote and conduct patient-centered research, disseminate findings, and optimize impact for the MS community.

Conduct research studies to gather the evidence needed in areas of greatest importance to people affected by MS.

Disseminate the evidence generated through iConquerMS research studies to relevant stakeholders with guidance on how people affected by MS might apply this evidence to their own needs. Use this evidence where possible to promote advocacy, shared decision making, and quality improvement processes.

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 by connecting those with MS, care partners, clinicians, and researchers, and to work together to accelerate innovation, research, and the application of new knowledge.” This innovative initiative has made significant progress toward achieving its goal. In less than 4 years, the network has grown to over 4,500 registered members. Almost

3,000 members have contributed data about themselves and their experience of MS as part of the network's [REAL MS™](#) (Research Engagement About Life with MS) research project. To date, iConquerMS has collaborated with researchers and organizations to enable and accelerate 11 research initiatives.



Representatives from many stakeholder groups attended this year's Leadership Summit (people with MS, care partners, industry, researchers and advocacy). The team's discussions had three main areas of focus, all laying the groundwork for developing transformational collaborations: building continued momentum and energy for iConquerMS, diving deeply into an understanding of the diverse needs and wants of the different stakeholder groups, and building and strengthening connections with each other in order to best fulfill the purpose and vision of iConquerMS. In one of the most powerful sessions at the Summit, participants divided into stakeholder groups, self-identifying as a person living with MS, care partner, researcher, member of industry, member of an advocacy organization, or health care provider. Each stakeholder group discussed such questions as "What do you want the others to know about your group?", "What's important for them to understand about your world?", "What are some of your primary challenges as a member of this group?", and "How could your group benefit from collaboration?" Each stakeholder group then shared their answers and all Summit attendees listened and asked questions to gain a better understanding of their needs, priorities, and contributions. The following insights were gained from these discussions:

People with MS

We are individuals, not a group that can be lumped together (we all have MS, but not much else aligns). We own our MS and have a voice as self-advocates. Don't discredit us because we are not scientists, we are experts because we live the experience. Our challenges include the stereotype of what MS looks like ("You don't look like...", "You should be ..."), as well as the hidden issues in MS (pain, MS hug, cognition and fatigue). Collaboration would be of great benefit to increase awareness of and education about MS. Researchers need to know patient concerns to drive relevant research. We want other stakeholder groups to work towards understanding each other (patients to doctors and doctors to patients) and listen to the patient, we know what we need. See us as individuals and recognize that it's difficult to be a patient and not every symptom is MS. Listen, be transparent, collaborate and share information, treat us with respect and dignity.

Care Partners

There's no time or place to address our needs and express our feelings. The rigors of being a support partner, dealing with invisible symptoms in people with MS is challenging. We have a tremendous amount to contribute about our loved one, frequently our perspective of symptoms is different. This input needs to be valued and respected. Collaboration with health care providers would be of great

benefit, as we are not often asked for input. Involve us, use us to help recruit for research studies, and do meaningful studies on care partners.

Industry

We care about patients. The perception of pharmaceutical companies as the “dark side” or villain is hard. We’re trained in medicine and other fields and we care about people. We have a desire to improve lives. We need to frame what we’re trying to accomplish in regards to our organizations. We work in a complex and heavily regulated environment. Your insights impact all of our work. We want to collaborate. Collaboration would help us identify unmet needs, provide focus and assist with the direction of limited resources. Involve us, look to us for our expertise and our interest in helping.

Researchers

Research is difficult. There is a need for more funding and scientific rigor. Research is iterative, what data is collected today is amplified or negated by data collected tomorrow, and negative results aren’t published. Patients can provide more meaningful questions. We need input from underrepresented populations -- men (especially in terms of MS), and minorities in general. It’s important to have placebo-controlled studies, but they are very hard to recruit for. We don’t have the understanding of the best process of engaging patients in research. We need to work together to develop methodologies.

Advocacy

It’s hard to know if what we are doing is making a difference on individual lives. Our challenges lie in establishing priorities. It’s important to collaborate when resources are limited, we can accomplish more. We would love help reaching the underserved, establishing priorities, and letting us know when we’re making an impact. We can work together to define these metrics.

On the second day, the group tackled the topic of transformational collaboration. Stimulus questions for discussions included, “What might transformational collaboration mean?”, and “What does it take to build and sustain transformational collaboration?” These inspired discussions led to the following definition:

Characteristics of a Transformational Collaboration

Shared goals and priorities: The collaboration is focused on achieving the goals of all parties in the collaboration - not the situation where some parties, for example people affected by MS, are contributing to goals determined by one party. The collaboration rises above individual priorities to focus on a shared priority.

Equal partnership: All parties are equal partners in the collaboration, even when one party controls the finances.

Disruption of an ecosystem: The collaboration is focused on achieving a major change in the ecosystem in which all parties are involved - for example shared treatment decision- making or patient-

focused drug development.

Use of a novel process: The collaboration uses a novel process to achieve the desired outcomes -- for example, the Plan, Do, Study, Act iterative cycle used by Learning Health Systems.

Diversity of partners: The stakeholders participating in the collaboration are diverse in some way, or ways, initially -- priority, incentive, thought, etc. These “unlikely partners” respect and recognize their differences, are willing to be flexible, and come to a shared understanding. A contributing factor to the transformational aspect may be the large number of diverse stakeholders participating.

Transformative collaboration for iConquerMS™ bridges diverse stakeholder groups and reframes the research conversation and processes, supporting a shared aspirational mission that respects differences, encourages innovation, and delivers value.

Other powerful phrases associated with transformational collaborations from group discussions included “bridging differences, unleashing human energies, unlocking greater value, having greater impact, and creating relationships across cultures.”

The final session for this year’s Summit was an activity focused on what might be possible if we built transformational collaborations. Using a process called Open Space, attendees identified topics they felt could have substantial impact on the lives of people affected by MS and broke into small groups to explore each topic more fully. Each small group grappled with questions like “What might be possible?”, “What resources or actions might be needed?”, and “What might be next steps?” Topics discussed included increasing the research capacity of iConquerMS through increasing enrollment, inclusion of care partners in all areas of MS research and healthcare, diversity and inclusion in MS research, leveraging of resources for the education and support of those affected by MS, patient engagement with pharmaceutical companies, ageism, telemedicine and nutrition. Summit attendees were free to move around and contribute to each topic of interest to them. Each small group enthusiastically outlined a plan for their topic area and identified ways to move things forward. With the conclusion of the small group work, the two-day Summit had come to a close but the work has just begun! A “Next Steps Committee” (NSC) has been formed and they 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 (back to phones and email) and is making great progress building on the work of the Summit. Stay tuned!

Interested in learning more about iConquerMS and getting involved in this novel initiative? Email Sara at sloud@acceleratedcure.org.



**Unity is strength... when there is
teamwork and collaboration,
wonderful things can be
achieved.**

Mattie Stepanek