

December 2021 Newsletter



Aligning Vision With Impact

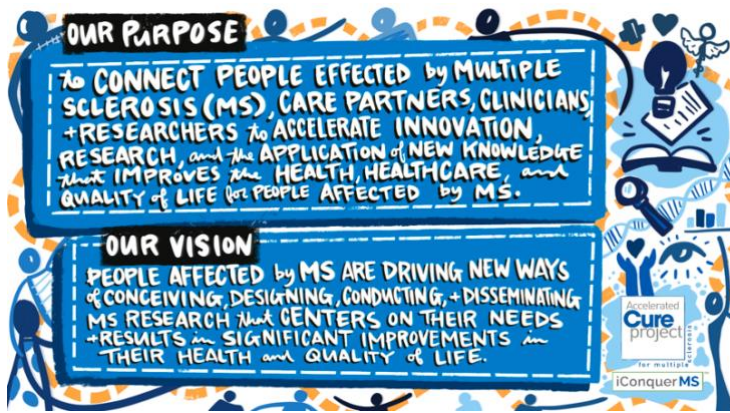
[iConquerMS™](#) was established to enable and accelerate MS research and other innovations with the goal of improving the health, healthcare and quality of life of people affected by MS. The initiative does this by connecting those with MS, care partners, clinicians, and researchers, and encouraging them to work together to accelerate innovation, research, and the application of new knowledge. Through iConquerMS, people affected by the disease are driving new ways of conceiving, designing, conducting, and disseminating MS research that centers on their needs and results in significant improvements in their health and quality of life.

In November, the iConquerMS governance and other stakeholders in the MS community gathered virtually at the 2021 Leadership Summit to discuss the future direction of the initiative. The key focus

A graphic of the year "2021" in a large, bold, orange and yellow textured font.

of this year's meeting was aligning iConquerMS's key priorities with our vision and desired impact. The meeting brought together a diverse group of individuals. One quarter of attendees were people living with MS. Other stakeholder groups present included researchers (13%), members of the iConquerMS governance (11%), members of other iConquerMS activities (11%), representatives from other MS

advocacy organizations (10%), care partners (7%), healthcare providers (7%), and representatives from industry (2%). Most of this year's participants were from the Boston area, followed by the Western US and the mid-Atlantic US.



This year's attendees kicked off day one of the Summit by discussing the importance of [equity and access](#) in MS research. Attendees revisited iConquerMS's guiding ideas (its purpose and vision), the initiative's role in MS research and what it is ideally

sued to do. They celebrated the [progress](#) the initiative has made increasing the awareness of and engagement in [participant-driven](#) (PDR) and [participant-powered research](#) (PPR). The group was challenged with the following question – “If iConquerMS, in partnership and as part of the MS community, is able to achieve its vision in 5 years, what would we need to either start doing, do differently or do more of?” Participants brainstormed what would bring iConquerMS closer to its vision, what they were excited to be a part of, and what would they like to make happen. The group explored what tools, resources, capacities, or partnerships would be necessary to move these topics and ideas forward. A number of proposed priority activities for iConquerMS emerged from these discussions, which are described below. Day two was focused on prioritizing these activities.

All in attendance at the Leadership Summit agreed that the initiative should keep listening to and amplifying the voice of people with MS in research. Priorities for the coming year include exploring ways to improve quality of life for people with MS, further expansion of the network's infrastructure, conducting more research through iConquerMS, and having more research questions driven by participants.

iConquerMS participants contribute their insights, expertise, and valuable health information to shed light on many aspects of living with MS. Summit attendees discussed ways to improve and use these valuable data to inform our priorities



and foster equity of research and care. All agreed on the importance of knowing the demographics of individuals in the database to ensure the research questions presented met the needs of the diverse population participating in iConquerMS. Additionally, attendees agreed that disaggregating the database as much as possible would enable a richer and more meaningful understanding of the various groups engaged.

The dissemination of research results was another main area of discussion. The group agreed the network should create a plan for the dissemination of research results in easily understandable language and include this plan in the design of all research done through the network. This would ensure that research has more of a direct impact on health and quality of life of those in the MS community. Attendees suggested that sharing results broadly with the MS community (instead of just with participants that completed a given survey) would engage researchers and increase their involvement in iConquerMS. It would also serve to attract people with MS to the initiative and increase enrollment. Another suggestion for improving the dissemination of research results was sharing “raw” data (instead of data that has been digested into “outcomes”) with network members and then convening groups to discuss the data. This would have the added benefit of not just sharing results, but also helping people understand them.



A number of exciting ways to increase the awareness of iConquerMS among all stakeholder groups were proposed during this impactful weekend. This would not only help expand the network, but also help build trust and equity by broadening engagement with a wider community in research. One idea was to develop a formal communications strategy and calendar which would communicate information about the initiative in an understandable way to a larger audience. Increasing the initiative’s presence on social media may also help in this regard, for example by making photos and posts more personal (featuring network members) or attracting more social media-savvy individuals to promote iConquerMS’s vision. Other ideas included connecting with individuals and groups that don’t use smart phones or computers and making better connections with people in rural communities. This could be



accomplished by creating a printed newsletter for dissemination to places where people might not have access to internet or web resources. The group discussed other outreach approaches like connecting with researchers and informing them of the value of iConquerMS, doing market research to

determine people's preferences for hearing information, and developing an engagement strategy for groups like the newly diagnosed and those that are not already engaged with iConquerMS.

Engaging with healthcare providers about iConquerMS and the benefits it could provide for their patients was another important topic of discussion. The group agreed that educating clinicians and researchers about the needs and priorities of people affected by MS should be a priority in the coming year. Helping them understand that hidden symptoms such as sleep disorders, bladder issues, bowel dysfunction, depression, and [social determinants of health](#) can have a huge impact on those living with the disease. Teaching researchers and study personnel about appropriate language to use when interacting with individuals with MS (for example, using "person" or "individual" rather than "patient" and not using acronyms like "PwMS") may help with recruitment efforts.

Summit participants discussed ways to diversify the iConquerMS membership. The conversation yielded some interesting pathways forward, including determining what historically underrepresented populations need and want from research. What do they need from a research network like iConquerMS? What is most important to them? Other proposed solutions were meeting with minority community leaders, conducting the research in under-served communities, and focusing on representation for minorities.

All agreed that improving the iConquerMS user experience would likely increase enrollment in the initiative. The importance of teaching and providing more support/training to all iConquerMS participants, ensuring they understand research

fundamentals, was stressed. Educational resources about living with MS could be



based on information obtained from the iConquerMS community. Improving usability and options for new members were also suggested as ways to boost enrollment.



The majority of Summit participants felt that iConquerMS should continue its efforts to grow the network's community, fostering communication with and between iConquerMS members. Gathering and sharing individual stories within the network was one idea to boost camaraderie among members. Attendees also stressed the importance of diversifying the network and how it is important to continue to value the representation of all people and stakeholders within it.

The group brainstormed ways to enhance and build collaborations with other MS groups and influencers in the upcoming year. This could be accomplished by gathering information about collaborative processes from industry. For example, what has worked for them in reaching diverse groups of patients? Partnerships relating to pediatric MS may be expanded by sharing information about iConquerMS through the channels that young people use, for example social media platforms like Instagram. Attendees also discussed ways to increase the initiative's political advocacy, perhaps by forming a Social Action Subcommittee to influence MS-related policy.

One of the biggest hurdles for the iConquerMS initiative to overcome is how to raise enough money to accomplish these goals. Summit attendees agreed that it's important to align the network's interests and priorities with all stakeholders to create momentum behind funding opportunities.



The 2021 Leadership Summit was a celebration of the work that has been done through iConquerMS in partnership with its stakeholders. This year participants deepened relationships and connections with each other. Over the course of the

weekend, attendees developed a shared understanding of the initiative's vision and what is needed in order to achieve it. The Next Steps Committee is focused on carrying the work of the summit and iConquerMS forward. We look forward to an exciting and productive New Year! Stay tuned!



Welcome to the Team, Kyle!

We are thrilled to introduce you to Kyle Shrivastava, the newest member of the ACP team! Kyle joined ACP in November as the Program Manager of the iConquerMS Research Inclusion Diversity and Equity (RIDE) Council, which is working to bridge the gap between awareness and full representation of racial, ethnic, and gender minority groups in research. Kyle brings with him a background in project management, stakeholder management, program design and facilitation, having most recently managed and supported international peace building projects for **PartnersGlobal**, a DC-based international non-profit. His experience and perspective will be valuable assets to the RIDE Council as they bring together diverse stakeholders within the MS community to



discuss and strategize on how to best build genuine partnerships that encourage minority participation both within the iConquerMS network and beyond.

Kyle is originally from Pennsylvania and, for the past 3 years, lived in Washington, DC. He and his fiancé recently purchased a house in Fort Collins, Colorado, and are in the process of settling in there. Kyle did his undergraduate studies at Bucknell University, earning a Bachelor of Science in Business Administration. He went on to graduate school at Columbia University and earned a Master of Science in Negotiation and Conflict Resolution. He has six years of experience managing international projects with a focus on participatory processes and cross-cultural facilitation. Most of his career has been focused on working with underserved communities.



Kyle spent three and a half years in West Africa early in his professional career. After graduating from Bucknell he worked in Senegal for two years as a community economic development agent with the Peace Corps. During that time, he helped women's groups form small businesses. For example, one of his main projects consisted of building a business around transforming and exporting rice, while another focused on helping entrepreneurs to powder and sell the leaves of the [moringa tree](#) as a nutritional supplement. After graduate school, Kyle went to Liberia to work with [Bosh Bosh](#) as a business development consultant through [Peace Corps Response](#). Bosh Bosh is a women's empowerment nonprofit that makes handbags and other textiles which they sell to fund a local girls' education program. After returning to the US, Kyle spent three years at [PartnersGlobal](#), managing peace building projects that spanned from West Africa, to Eastern Europe, and South East Asia. Kyle shares that the one of the most meaningful aspects of his time abroad was being part of the community in Senegal as a Peace Corps volunteer. In his words, "I lived with a local family in a household of ten or so. Coming from an individualist society, it was really eye opening to see how everyone worked together on a daily basis to contribute to the family's wellbeing. A lot of time was spent outside, sitting on mats in our open courtyard simply being with one another. It made me question the speed and purpose of my life in the US and has led me to ensure that family is always a central priority as I move forward."

When not at work, Kyle is a singer/songwriter and plays the acoustic guitar. He also enjoys drawing mandalas and other forms of geometric art. According to Kyle, “I usually only use black ink on paper but sometimes will dabble in digital art or watercolor. It’s a way to unwind in my free time.” Kyle is also a yoga instructor and co-founder of [Yoga Humans](#), a resource site for new and aspiring yoga teachers. He recently published his first book, [Feral: Returning to the Wild](#).



Kyle and his fiancé recently returned from a 6-month coast-to-coast camping trip that took a circuitous route across the United States, starting in Colorado and ending in Shenandoah National Park in Virginia. He shares, “We saved for two or three years and ended up converting my fiancé’s family minivan. We gutted it, put some cabinets and a bed in... We were living in a one-bedroom apartment in DC, it was crowded and we couldn’t leave the apartment without a mask. We were ready to get out of the city. We both quit our jobs and used the money we had saved to float us by. It ended up being a reaffirmation of the fact that when you see an opportunity you should take it. Thankfully, we came back and within a month or so, were both reemployed and in the process of getting resettled. It was a wonderful way to spend the pandemic, but I’m also at a point where I’m pretty happy to get back to work.”



Kyle was drawn to the position at ACP because it’s right up his alley. In his words, “Everything from my degree in conflict resolution to my work in facilitation and participatory processes has been approached through the lens of how do we create the most genuine and effective co-creation experience with local communities, politicians, advocacy organizations and nonprofits. When I saw this posting, I recognized that this was the same approach ACP was aiming to take. This question of how to help move the medical field towards research that’s designed, implemented, and co-led with constituent communities including those that represent racial minorities is incredibly exciting and absolutely necessary.”

When asked about his vision for the RIDE council, Kyle states, “What we often see in research is really great data that doesn’t always translate to action. As I see it, the RIDE

Council will be harnessing community knowledge so as to build off the existing research that ACP has conducted on the complex dynamics between minorities and researchers, the ways they are engaging, and the communication gaps between them. We'll then work to translate our understanding into actionable impacts and outcomes. On the simplest level, we hope to see our impact in terms of a level of minority participation in the iConquerMS network that's proportional to the US population. In broader sense, we also hope to build some replicable models that demonstrate how minorities can be equitably and fairly represented not only in MS research, but in all medical research... To me it's stunning to think that for so many years, the medical field saw MS as a Caucasian disease while data now suggests that incidence rates may be higher in Black communities and more severe in Latinx groups. It seems like the time is ripe, if not long overdue, for us to gain an inclusive and accurate understanding of our country's medical needs. Furthermore, we need to go beyond only thinking about how to reach these populations, and instead also reflect on how we can build genuine and mutually beneficial partnerships that are equitable and inclusive from design to dissemination. We need to think about what an authentic partnership looks like. What an authentic relationship with a community looks like. We need to learn how and when to relegate leadership. Truthfully, I don't think many people know, regardless of their roles within the medical or patient communities. Hopefully, together we'll figure it out."

We are excited to have Kyle on board, lending his experience and insight to the RIDE Council. Their work to diversify MS research will bring us one step closer to ensuring that its findings apply to and benefit people of all racial backgrounds, allowing all individuals living with MS to receive the best care possible. The prospects for 2022 are looking bright! Stay tuned!



December 2021 iConquerMS Spotlight



Join in accelerating MS research through iConquerMS!

There are a lot of exciting things going on at iConquerMS right now. Here are some of the ways you can join in!

Join Now

If you are not already a member of iConquerMS, please consider [joining!](#)



Share your MS diagnosis experience. Visit your [dashboard](#), click on "View and Complete My Research Studies" and complete the "MS Diagnosis Experiences" survey.



Complete your [REAL MS surveys](#). Your Data has Power!



Help keep MS research focused on the needs and priorities of people living with MS. Participate in the [Our Questions Have Power](#) program.



Share your experience with COVID-19 vaccines through [COVER-MS](#).



Participate in other surveys and focus groups. Filling out your [REAL MS surveys](#) is the best way to be informed of these opportunities!



Have special skills like community building, outreach, development, graphic design or writing? [Volunteer](#) your talents to advance iConquerMS's work!

December 2021 Research Spotlight

RESEARCH OPPORTUNITIES



**Your health data
has power!**

A new topic for the Our Questions Have Power program!

When it comes to MS symptoms and how to manage them, what questions are most important to you? What symptom-related topics do you wish researchers were studying? **Your questions are valuable** and we invite you to share them through the **Our Questions Have Power** program on the [iConquerMS](#) website.

[The Our Questions Have Power program](#) was launched in March with an initial focus on COVID-19. Questions submitted by iConquerMS members have helped shape the [COVER-MS vaccination study](#) and are being shared with the research community to guide other efforts.

We're now extending Our Questions Have Power to include a second topic: **MS symptoms and their management and treatment**. As before, you're invited to share questions on this topic that you think should be studied and to vote on questions submitted by other iConquerMS members.

We'll share these questions with people affected by MS, researchers, healthcare professionals, advocates, and funders – and, together, we'll work to launch research studies to answer those questions.

It's easy to share your ideas and input in Our Questions Have Power!

- Log into [iConquerMS](#) to start (create an account first if you don't already have one).

- Have a research question to submit? Click **PROPOSE an MS Research Question** to submit a question you'd like to see studied.
 - Want to weigh in on other people's ideas? Click **VOTE and COMMENT on MS Research Questions** to review, comment, and vote on questions submitted by other iConquerMS members.
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Share your MS diagnosis experience

Receiving a diagnosis if MS is a life-changing experience. The support and information given during the process can vary greatly from person to person. A team of researchers from the US and Italy are studying the diagnosis experience for people with MS to learn about ways in which the process could be improved. They are also interested in learning how people with MS prefer to disclose, or not disclose, their diagnosis to others.

You are invited to help with this study by taking a survey available on iConquerMS. This study is open to all iConquerMS members who have been diagnosed with MS. We hope you will take part!

Study participants will be entered into a drawing for an Amazon Gift Card. We will be awarding twenty \$50 gift cards and forty \$25 gift cards.

Who can participate?

Anyone who has been diagnosed with MS.

What does the study involve?

The study involves completing an on-line survey on the iConquerMS web site. It will take approximately 20-25 minutes to complete.

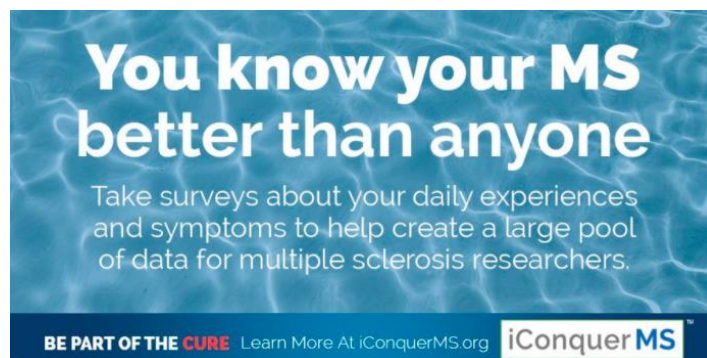
Who is funding the study?

The study funder is the University of Vermont.

How can I take the survey?

Log into your account at www.iConquerMS.org and click the button that says, “View and Complete my Research Surveys.” You’ll see a survey named “MS Diagnosis Experiences.” Click on the survey name to get started.

If you have any questions, please email us at info@acceleratedcure.org and we’ll be happy to help. Thank you for helping us learn about and improve the diagnostic process for MS!



Complete your REAL MS surveys!

In the summer of 2016, the iConquerMS initiative launched REAL MS (Research Engagement About Life with MS), a longitudinal study of MS. Participants complete questionnaires online twice each year on a variety of subjects, including health history, diet, exercise and their experience with MS. **The next round** of REAL MS surveys is available

now through the [iConquerMS portal](#). Completing these surveys is one of the simplest ways you can accelerate MS research. The information collected 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. REAL MS is just one of the many ways iConquerMS is facilitating research on topics of importance to people affected by the disease. If you are not already a member, please consider [joining](#) iConquerMS, the only people-powered research network for MS!