

November 2021 Newsletter



Collaboration – We’re Better Together

According to [dictionary.com](https://www.dictionary.com), “Collaboration is the act of working together, especially on a goal or shared project.” Since its inception, collaboration has been at the heart of ACP’s work and mission. The [ACP Repository](#) was established in 2006 as a source of high-quality samples and associated data that is readily available for MS research studies. If samples are used, researchers must return their results to the Repository database, so they can be shared with others (thus fostering collaboration within the research community). [iConquerMS™](#) was launched in 2014 as the only people-powered research network in MS. This powerful initiative brings together and enables people with MS, their care partners, researchers, healthcare providers and others to work together to help drive MS research forward. According to ACP’s CEO Sara Loud, “To me, the collaborative nature of our work is most exciting... A complex disease like MS is unlikely to be cured in a fragmented research environment. There is a tremendous need for collaboration in order to accelerate MS research toward better ways to diagnose, treat, and eventually cure the disease.”



ACP and iConquerMS are changing the landscape of MS research by increasing the awareness of and engagement in [participant-powered research](#) (PPR). We are grateful for all that have partnered with us to make this movement possible. Over the past seven years, iConquerMS leaders, network members, researchers, healthcare providers and other advocacy organizations (among others) have joined in an ongoing collaboration to determine ways to successfully drive PPR forward. The group has worked to engage researchers and inform them of the potential iConquerMS holds as a powerful resource for their studies. They've helped investigators better understand the patient perspective and create research plans collaboratively to ensure they are "doable" for intended participants. Facilitating funding for PPR has also been a main area of focus. This cooperative effort has been and will continue to be an activity that brings together all of the major stakeholder groups in MS research.



[iConquerMS](#) has partnered with a number of investigators on studies looking at a wide variety of subjects related to living with MS. For example, [STEP for MS](#) (Supervised versus Telerehab Exercise Program for People with Multiple Sclerosis) is a collaborative effort between seven research sites in the U.S. and iConquerMS. This four-year study compares the outcomes of a 16-week exercise program conducted either at home, or in an exercise facility. The researchers conducting the study hope that the findings will make exercise and its benefits more available to people with MS who have problems walking. iConquerMS has also been a key resource for exploring the COVID-19 crisis and its impact on people with MS. As part of an [international data collection](#), network members were polled in April 2020 to learn more about how they were dealing with the pandemic and what their personal experience had been with the (then) new coronavirus. Data collected through this effort is acting as a stimulus to steer ongoing and future scientific research. In collaboration with researchers at Case Western Reserve University and Massachusetts General Hospital, the iConquerMS research team is conducting the [COVER-MS study](#) ([C](#)OVID-19 [V](#)accinE [R](#)esponse in [M](#)S) to collect information from iConquerMS members related to their experiences with COVID-19 vaccines. These real-world results provide a better understanding of the effects of these vaccines in the MS population. We look forward to more exciting research collaborations in the future!



in a way that is similar to the care partner expansion of the network. This effort is being overseen by a steering committee comprised of youth and parents living with MS, and is co-led by [Emily Blosberg](#), founder of [Mr. Oscar Monkey](#). Through this powerful collaboration, families will be able to contribute valuable data to shed light on many aspects of living with pediatric MS, help steer the future direction of MS research, and may one day play a role in unlocking the answer to a cure.

Samples from the ACP Repository have played an instrumental role in understanding the genetic underpinnings of MS. The [International MS Genetics Consortium](#) (IMSGC) is an international cooperative, composed of members from academic institutions all over the world, founded on the principle that collaboration will lead to more rapid progress than can be achieved individually. In 2019, the IMSGC published the largest MS genetics [study](#) to date. As part of this research, DNA samples from the ACP Repository helped to confirm 233 variations in the human genome that contribute to the risk of developing MS. The variations were found to influence many different types of immune cells and tissues, indicating that general dysfunction in the immune system underlies the onset of MS. The study also identified a genetic variant for MS on the [X chromosome](#), which could be an interesting lead to investigate why women are more likely to develop MS than men (women have two X chromosomes while men have one). The IMSGC is a prime example of the collective power of patients, researchers, and funders coming together to accelerate important research into the genetic markers that are associated with MS. In 2018, the entire [exome region](#) of the more than 3,200 DNA samples in the ACP Repository was sequenced as part of a [collaboration](#) with Regeneron Genetics Center. Combining this new genetic information with the extensive participant and clinical information collected for each ACP Repository participant will lead to new insights into the causes and mechanisms of MS. Threads from this research are generating additional collaborations, which will expand the pool of returned data that researchers can draw from as they work to understand the mechanisms of MS. All ACP Repository participants have contributed to this unprecedented combined data set. Thank you!





ACP's partnerships with [RealTalk MS](#) and [Smart Patients](#) help people with MS learn about, talk about and engage with research and with each other. As a member of the [MS Coalition](#), ACP is able to come together with other MS nonprofit organizations and leverage its resources for the benefit of the entire MS community.

According to Sara Loud, “None of our work would be possible without our partners. I am grateful for the collaboration of our iConquerMS members and our Repository participants, for the researchers who engage with us to advance their work and the funders who make that work possible, for the leaders in other nonprofit organizations and throughout industry who share our desire for better outcomes for those impacted by MS, for the donors who support ACP in recognition of the importance and value of our contributions to accelerating research and innovation to improve the lives of those affected by MS, and to all of you who guide us with your insights and feedback. The list of those who make our work possible is long... We are guided by the needs and priorities of those affected by MS and can only do our best work when you are part of it. I am looking forward to all we will accomplish together in 2022 and beyond.”



An award-winning essay

[Pediatric MS](#) isn't common, affecting just [two to ten percent](#) of people with the disease. Nevertheless, when a child or teen is diagnosed with MS, the entire family is significantly impacted. [Mr. Oscar Monkey](#) is a nonprofit organization, founded by Emily Blosberg, that supports children and their families on their journey with MS. They host regular retreats and Zoom calls that help children and teens living with the disease, and their families, connect across the nation and world. Emily recently started a scholarship fund through Mr. Oscar Monkey, offering fifteen \$1,000 scholarships to high school seniors with MS. Applicants were asked to write an essay about their MS journey, their involvement in the MS community and their post-graduation plans. Alivia Cook is the recipient of one of these scholarships, which was sponsored by ACP.



Alivia was diagnosed with MS in 2019, when she was a sophomore in high school. She had trouble with her vision for 2 weeks. In her words, “I woke up ready to start the second semester, but I could not see clearly. I had these black spots in my vision, it was as if I was looking through Swiss cheese.” She went to an optometrist and an ophthalmologist, who couldn't find anything wrong. Her mother thought it was just a migraine. However, when an MRI revealed she had lesions, she was diagnosed with clinically isolated syndrome. Six months later, the first day of her junior year, she experienced numbness in her right arm and leg and was rushed to the emergency room. She received a 5-day course of steroids and was diagnosed with MS while she was in the hospital. A month later, her neurologist started her on disease modifying therapy. According to Alivia, “When I took Gilenya my heart rate was too low and I had to spend another night in the hospital. They started me on Tecfidera about 2 weeks later and since then that's helped a lot.”



At first Alivia tried to hide her diagnosis from her teachers and friends, “I tried to downplay my feelings about it, saying ‘it's no big deal’ or ‘hey, it could be worse’ because it's hard to tell the people you care so much for that you have a chronic illness. It was also hard for me to accept my new reality...In the beginning I missed a lot of school. I missed a week for my spinal tap. That was when I decided I

had to be more open and honest. When I came back to school, my chemistry teacher said you don't have to tell me what happened. I just want you to know I'm here for you and I've got your back...Fortunately, I have a really good group of friends. I remember telling them about my diagnosis and one of my friends said, 'whatever it is, we can get through it together'. I think about that a lot. I know it was definitely rough on my friends but going through it with them was really good. It made it a lot better. I realized that I had a whole other community to support me. I know they'd be there to help me every step of the way."

When asked how her MS diagnosis made her feel, Alivia states, "It wasn't easy accepting my diagnosis. I think a lot of that was me pushing down my feelings about it. I felt sad for a long time because I was really confused. I had a hard time understanding what I had



done wrong for this to happen. Anytime someone would ask me about it I would feel like I was about to cry. Even though I had all this outside support, my inside support system was not catching up. One of the social workers who saw me when I was in the hospital recommended that I start therapy. She said it helps a lot of children who are recently diagnosed with chronic illness to just talk it out in the first couple of months. Therapy has helped me a lot. It's really nice to get a clear, unbiased perspective from someone who's not an immediate part of your life, like a parent or a friend. Over time it got easier and easier to talk about and one day it all just clicked and I felt a lot better. I started talking to my friends and family about my fears. Being bogged down with my thoughts about MS made me miss a lot; it removed me from the world. It was like I was hovering over everything but eventually my feet felt the ground and I took off running. I got back to school. It took me some time to catch up, but I got there. I got back into my sports, clubs and activities." Alivia shares that facing her MS diagnosis has taught her a lot about herself. "I'm more resilient than I thought I

was. I've had a lot of setbacks with this and I get down about it sometimes, but I just pick myself up and brush the dirt off and I just keep going until I hit the next bump.



Then I stumble a little bit and just pick myself back up and keep going."

Once Alivia came to terms with her MS diagnosis, she got to experience some of the greatest moments of her life. She received her second varsity letter in debate, went to prom with her friends, had a fantastic outdoor track season and took a memorable trip to Italy with her family and about a dozen fellow students from her school. She states, “It was really nice to have that break and immerse myself with new people and experiences.” She is currently a freshman in college at Case Western University and would eventually like to go to medical school and specialize in pediatrics.

Alivia’s family was also impacted by her diagnosis. In her words, “I have always had a small family, just me, my mom, and my grandparents. They were devastated at first but have been pretty strong. It was the hardest on my mom, she’s a single mother and I’m her



only child. We’re pretty close and stuck together through it. My family is now doing everything they can to support me. My grandma comes to my doctor’s appointments with me and makes her list of questions to ask the neurologist every time we go. My mom is always researching new therapies or new advancements in MS research.”

Alivia didn’t know any other kids with MS when she was diagnosed, but she did know three adults. In her words, “When they heard I had MS they started talking to me about the different treatments and how MS has affected them in their lives. That was comforting to hear, but it wasn’t as relevant to me because they were all diagnosed as adults.” Alivia learned about Mr. Oscar Monkey about a month later. She shares, “I came home from school to find a package in the mail. It contained an orange sock monkey. I was still put off by my MS at the time. I thought, ‘what did my mom do?’ She was still at work, so I texted her and she sent me a link.”



Alivia has attended Mr. Oscar Monkey’s camps for the past two years and she periodically attends their calls. She states, “When I went to my first retreat, I wasn’t at terms with my MS diagnosis and wasn’t as open. I don’t feel like I got as much going there as I could have if I went with a more open mind. Getting to know Emily, her family and the other children with MS allowed me to build up a community of people that I didn’t know I was able to have, one that really understands what I’ve gone through. It gave me a new

perspective on MS. The disease is so different for everyone. Everyone at Mr. Oscar Monkey refers to MS as snowflakes because we all have a different story. It's good to hear how other people experience some of the similar things you do. There was a girl who was recently diagnosed at one of the camps this summer and it was nice to talk to her because we had similar symptoms and she felt the same way I did when I was first diagnosed. It was kind of like looking at myself and I feel like I was able to help her. I also think it's been really beneficial for my mom to talk to other MS moms. She's gotten to know some that she met at the buddy bash and they're able to bounce ideas off of each other for similar problems."



When asked what she would say to a child or teen that was considering joining Mr. Oscar Monkey, Alivia replies, "I would say I was definitely hesitant at first. My mom forced me to go and it was a really good thing she did. The community that

Emily has built up is truly amazing. I wish I had been more open and more involved earlier because the people you meet, Emily and her family, they care so much about each one of us. They really take the time to get to know you and make you feel supported. They make you feel like part of their family." According to Alivia, "MS is not something that anyone wants, it has taken a lot from me, but it also has given me much more. It has shown me a support system that spans across the country and has also brought my family and I closer and made us understand each other more. It gave me a new community to interact with, a new drive. I'm interested in going into healthcare, but I've also seen how Emily and the other MS kids advocate for public health and public policy specifically surrounding MS. I also think it's given me a drive to advocate for people with chronic illnesses. Trying to find ways that I can do more for this community that has given me so much."

The vast majority of MS research focuses on the adult MS population. Alivia states, "I think it's important to find ways that children and youth can participate in research studies for MS. Many people say that kids can't get MS. A lot of kids are misdiagnosed at first because the disease manifests itself so differently in children and adults. It's necessary to be able to identify the different symptoms that children and adults might experience." With the support of a PCORI Engagement Award, iConquerMS will be expanding

enrollment to include children and teens with MS and their loved ones. Emily Blosberg is co-leading this project, lending the insight and experience she's gained working with the children at Mr. Oscar Monkey. Through this effort, families will be able to contribute their insights, expertise, and valuable health information to shed light on many aspects of living with pediatric MS, help steer the future direction of MS research, and one day unlock the answer to a cure.



November 2021 iConquerMS Spotlight

The next Chat with Chat webinar is coming soon!

The Next Steps Committee of iConquerMS has launched a new webinar series called “Chat with Chat” and you’re invited! Hosted by our research collaborator Chat Ngorsuraches, these conversations provide a glimpse at the researchers working with iConquerMS, what they study, and how their work will benefit people with MS.



The next webinar, entitled “COVID-19 and MS: Lessons Learned from iConquerMS,” is scheduled for December 10, 2021 at 2 pm Eastern. Dr. Farrah Mateen will be the guest speaker. Anyone interested in attending, please register [here](#).



A heartfelt thank you to Chat and his colleagues for making this educational resource possible. Stay tuned for future episodes!

In case you missed previous episodes of Chat with Chat:

In [Episode 1](#), Chat spoke about his own research into the aspects of MS drugs that people value the most.

In [Episode 2](#), Chat spoke with Nina Bozinov, MD MS, about "Measuring the Quality of Life of People With MS: Findings From the REAL MS Study." If you’ve participated in REAL MS, this is a great chance to learn what your data is telling us about life with MS. P.S. The 2021-2 REAL MS surveys are still open! If you are a member of iConquerMS, why not [complete yours](#) today?

November 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. 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.
-



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!



A New MS Aging Study

Our research partners at the Albert Einstein College of Medicine in New York City are conducting a study of aging and walking in MS.

What is the study?

The goal of this research study is to evaluate how the brain is involved in walking in older adults with and without MS. The results will provide valuable new information about how brain structure and function affects the ability to walk and influences the risk of falling. If successful, the findings may lead to possible new treatments that could improve brain control and efficiency of walking.

What is involved?

Participation begins with a telephone interview to see if the study is a good fit for you. If it's a good fit, and you agree to participate, you will have two study visits around 3 hours long at the research center at Albert Einstein College of Medicine. You will be asked to fill out some questionnaires, complete a few tests that assess cognitive functions (e.g., memory, attention), participate in some walking tests, and have one MRI.

The research team will arrange free private transportation to and from the research center for each visit. You will be paid \$100 for each visit for a total of \$200.

The research team strives to make your experience a positive one and has put in place several precautions to ensure your safety during the pandemic. The staff is vaccinated, always wear masks, and maintains appropriate distance. Study visits are conducted with only one person at a time.

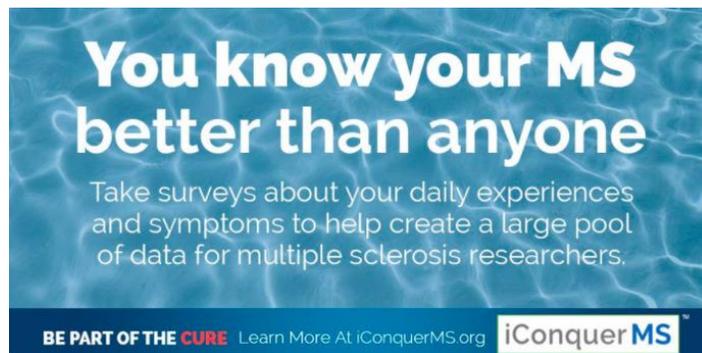
Who can participate?

The researchers are looking for people who:

- Are at least 60 years of age
- Have been diagnosed with relapsing remitting MS (RRMS) or secondary progressive MS (SPMS)
- Can walk 20 feet without assistance or with a single-point cane
- Have been on the same MS disease-modifying therapy for at least 6 months
- Meet additional study criteria

Interested in participating?

[Complete this form](#) to let the research team know of your interest. You can also call or email them at 718-430-3972 or holtzer.neuropsych@gmail.com



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!