

December 2019 Newsletter



Hello everyone and Happy New Year! I hope that during this busy time of the year, you are finding opportunities for rest and relaxation. At ACP, we are busy tying up the loose threads for our 2019 activities and making plans for all we will accomplish to accelerate and advance MS research in 2020.

As I've been with ACP for more than 14 years, many of you have "met" me or at least seen my name – most likely in regards to the ACP Repository (I joined the organization as Repository Director many years ago!) or perhaps more recently as COO. If you are a member of iConquerMS, you most certainly have received an email or two from me inviting you to respond to a survey, contribute your insights to a study design, or sign up for an opportunity to engage with researchers directly by sharing your experiences as a person affected by MS. But today I'm writing to you in my new role as CEO of ACP. It's my pleasure and honor to take on this position within the organization. I'm looking forward to working with our staff of six, our Board of Directors, with all of our collaborators and partners in the MS community, and with all of you to continue our work of accelerating MS research to improve the health, healthcare, and quality of life of people affected by MS.

I joined ACP after working in high tech as an engineer for many years. While I loved the challenge of solving complicated problems and seeking out effective and impactful solutions in the engineering start-up companies I worked for, I felt disconnected from the end result. I'm glad that someone wants to build a terabit switch router for the Internet but I knew it didn't have to be me. So, I went to business school and focused on social enterprise, with the intention of applying my technical and business skills, combined with my love of innovation and problem solving, on something closer to my heart. When I heard about ACP and of their approach to accelerating MS research through the creation of centralized, openly accessible research resources, available to researchers anywhere in the world, and with a focus on breaking down barriers and fostering true collaboration, I knew it was the perfect place for me. Fast forward 14 years, and I still feel the same way.

In the years since I've joined ACP, we've enhanced our offerings beyond the original [ACP Repository](#) to include [iConquerMS](#), our people-powered research network, and the [MS Minority Research Engagement Partnership Network](#) (MREPN). Each of these initiatives is built on the core principle of collaboration, a philosophy at the very heart of all we do here, and together are reflective of our focus on accelerating research on topics of the greatest importance to all people affected by MS, driving toward faster diagnosis, more effective treatments (including and especially those beyond pharmacological ones), and ultimately, a cure for the disease.

As we look toward 2020, we will continue to align our work at ACP with the priorities of those affected by MS. Through iConquerMS, we will be developing a process for Participant-Driven Research – to capture, prioritize, and move towards funded research on the questions identified by our members as most important to them. We will also continue to bridge our iConquerMS community with researchers, to ensure that the voices of those affected by the disease are central to research and development, innovation, and impact. We will expand our engagement within the MS community to better address the needs of care partners to those living with MS, and begin a focused exploration into the needs and priorities of children and teens living with MS and their families. We will build upon the work of both iConquerMS and the MREPN to address barriers to participation in research from members of communities of color, focusing on the inclusion and engagement of people affected by MS from racial and ethnic minority populations, to ensure that research studies and the evidence produced are reflective of the diversity of the population of those living with MS. And we will continue to seek out scientists interested

in accessing the samples and data in the ACP Repository, including the unprecedented combined data set we are building with research results from researchers across the world who have used the Repository, as they move towards increased understanding of the mechanisms of MS, and toward a cure.

None of the work we have set out to do will 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.

I invite you to connect with [me personally](#) and with any of the [staff at ACP](#) at any time. 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 2020 and beyond.

Happy New Year!

A handwritten signature in black ink, appearing to read "Sara". The signature is fluid and cursive, with a large initial "S" and a long, sweeping underline.

Sara