

# November 2020 Newsletter



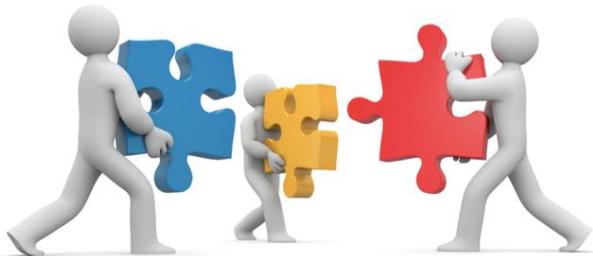
## Thank you for the Teamwork!

[iConquerMS™](#) (iCMS) brings together people with MS, their care partners, MS researchers, healthcare providers, funders and other stakeholders to improve the health, healthcare and quality of life for people affected by the disease. This groundbreaking initiative enables everyone affected by MS to contribute to new breakthroughs in MS research. We are grateful for the participation of many individuals and organizations who have contributed to its success.



A number of stakeholders played a key role in the creation of iCMS. Without them, we wouldn't be where we are today. The [ACP team](#) has led the initiative since its inception, driving efforts to build and grow the initiative. The [Patient-Centered Outcomes Research Institute](#) (PCORI) provided the funding needed to build and operate iCMS for the first five years and continues to fund components of the initiative today. Feinstein Kean Healthcare (now incorporated into Ogilvy) led the strategic planning for the network and the development of initial outreach and visibility efforts. Complex Adaptive Systems at Arizona State University partnered with Life Data Systems Inc to develop the IT components underpinning iCMS. These components allow people affected by MS to

easily and securely contribute their health data, insights, and expertise through the [iCMS portal](#).



The iCMS governance structure includes a Governing Board and two committees. The Governing Board oversees all iCMS activities. The Engagement Committee focuses on recruitment of new members and engagement with current members,

and the Research Committee serves as a link between researchers and the iCMS community. Most iCMS board and committee members are people with MS. This enables the initiative to stay focused on the needs and interests of people affected by the disease. Highlighted below are three individuals who help with the iCMS governance in different capacities. We are grateful for their hard work and the efforts of many other individuals who serve behind the scenes to make this innovative initiative possible.

### **Thank you to the iCMS Governance**

Heather Siefers was formerly the Biorepository manager for the ACP Repository, and is now Chair of the iCMS Governing Board. She was diagnosed with MS in 2003, at the age of 28. In Heather’s words, “Prior to iCMS, I did not have a network of individuals living with MS with whom I could connect and share my experience. Being on the Board has allowed me to find my MS ‘family,’ where we can provide support to each other, advice, and encouragement.” According to Heather, the Board’s biggest challenge is developing and cultivating a forward-looking strategy for the initiative. When asked what she enjoys most about her role, Heather states, “Being able to infuse the patient voice into research has been an incredible and rewarding experience. Pioneering the concept of bridging the divide between the various stakeholders (e.g. Pharma, researchers, patients, care-providers) has showcased the strengths of iCMS and its leadership, of which I am honored to be a part.” Looking to the future, Heather shares, “I would like to see iCMS continue with its growth and sustainability strategy but with sustained emphasis on expanding the diversity within the organization to become a more inclusive representation of the MS patient population.”

One of Anita Williams' many roles at iCMS is Co-Chair of the Engagement Committee. When asked about her service, she states, "So much about MS can leave one feeling powerless and at the mercy of neurologists, clinicians, physician's assistants, radiologists, etc. Within the research community, iCMS places me, the person living with MS, at the center of the discussion. The power that is 'power in research' is me." According to Anita, the Engagement Committee's biggest challenge is finding enticing ways to reach new members in a way that is authentic to the initiative. In her words, "We have a lot to offer and we need to cut through the noise to reach not just new members, but potential advocates." When asked what she enjoys most about her work on behalf of iCMS, she shares, "The people!!! I get to collaborate and learn from some of the smartest, most passionate, and committed individuals around. I am blessed to know them." Anita's view for the future of iCMS is "Endless and boundless! So much is going on. So much is percolating under the surface. It's like that pot of water you wait to boil. At first you see those tiny little bubbles just popping like champagne. Then, the surface trembles a bit. Then \*bam\*, it's suddenly boiling. iCMS is that pot getting ready to boil that commands your attention."

Amanda Windhof lends her time and talents on the Research Committee. She was diagnosed with MS 5 years ago. In her words, "The Research Committee's role is to ensure that every research idea that is presented to us is of high quality, and there is a clear and well thought out research design. We also discuss new collaborations and keep up to date on ongoing research projects." Amanda enjoys the open mindedness of her iCMS comrades. She shares, "My biggest joy with this group is that, it doesn't matter what your background or experience is. If you have an idea to discuss with the group, everyone will listen and discuss. Coming from academia, this is a very different atmosphere than I am used to, and it is so refreshing. We are all experts in our own way, so all of our voices should be heard." Amanda feels the Research Committee's biggest challenge is balancing the desire to drive research forward and keeping iCMS members' best interests at the heart of every decision. When asked what she enjoys most about her role, "The people. I have been able to meet and interact with so many inspiring people on this committee, and they really listen to each other and consider everyone's ideas equally. That is really rare to experience." Amanda's view for the future for the initiative is limitless. "What I have learned about iCMS is they are determined to make pretty much anything happen that is important to people affected by MS. They have shown that they can adapt and grow to

encompass any challenge that comes their way. They are open to collaboration, which I see as one of their greatest strengths. So, I see the future of iCMS as ready for anything.”

We are grateful for our ongoing collaboration with many leading [MS organizations](#) and are thankful to a number of [MS clinics](#) for their leadership, commitment, participation, and support. We're proud to partner with organizations that help people with MS learn about, talk about, and engage with research, such as [RealTalk MS](#) and [Smart Patients](#) and appreciate their efforts to help spread the word about the work iCMS is doing.



We'd like to extend a heartfelt thank you to everyone who is contributing their health information, insights and ideas to iCMS. To date, the initiative has over 6,700 members from 58 countries and all 50 states, DC and Puerto Rico. Participants include people living with MS, family members, and other loved ones. This broad participation is vital for helping researchers better understand, treat, and ultimately cure MS. If you have MS, care for someone with MS, or simply want to support MS research, you are also welcome to participate. If you haven't already done so, please consider [joining](#) the iCMS community today and add your voice to the thousands already driving MS research forward!



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OF THE  
CURE**