

June 2022 Newsletter



Meet Our Newest iConquerMS Ambassador!

iConquerMS would not be possible without people and organizations who care about MS research and conquering MS. The iConquerMS Ambassador Program recognizes individuals that are dedicated to improving the lives of those living with the disease and ultimately finding a cure. It is our pleasure to introduce you to a researcher whose enthusiasm for serving the MS community is inspiring, our newest iConquerMS Ambassador, Surachat Ngorsuraches (Chat).



Chat is originally from Thailand and currently lives in Auburn, AL. He is a faculty member at Auburn University's Harrison College of Pharmacy, where he teaches their Doctor of Pharmacy program and their graduate program in Health Outcomes Research and Policy. His research areas include pharmaceutical economics and policy, focusing on patient preferences and patient-centered research.

As we discussed last month, the National MS Society recently sponsored [research](#) to investigate the economic impact of MS. As anyone living with the disease can attest to, their findings confirm that living with MS is very expensive. Dr. Ngorsuraches served on the advisory committee for this project. In his words, "The evidence presented in this paper can be used to advocate for policy changes in the future. Letting the legislature or

policy makers know that the economic burden for the patients and families is very high, especially for the cost of DMTs, enables them to work with the pharmaceutical industry or drug manufacturers to try and reduce the cost for the patient. Encouraging policy makers to support more MS research is another way to reduce the economic burden of the disease.”



There is a growing recognition of the importance of incorporating the [patient perspective](#) into every step of the research and development of new treatments. People living with conditions like MS are often faced with treatment choices in the course of their disease. They are the experts on what it’s like to live with chronic illness and the impact of treatments on their quality of life.

The patient’s point of view can be used to deepen the understanding of living with such conditions. Improving patient engagement throughout the industry and incorporating the patient voice into the design of products and services has great potential to improve patient outcomes which will, in turn, benefit everyone. Chat is a big proponent of patient-centered research. He states, “We like to improve quality of life for people with MS and their families. There are a lot of missing parts in the research that’s been done. These efforts can help people with MS to some degree, but we could do way better if we actually put them at the center of the research and engaged them throughout the research process.”

Chat received funding for two studies from the [Patient-Centered Outcomes Research Institute](#) (PCORI), which has also provided funding to ACP for the development and operation of iConquerMS. Both of Chat’s awards are [capacity building](#) projects to pave the way for future patient-centered research. In his words, “We work with



patients in phases. We start by talking with them about what they need in terms of training or knowledge to get comfortable enough to talk with the researchers or healthcare providers. Then we develop several trainings during which speakers and researchers are invited to spend time and talk with them. During the next phase we ask patients to brainstorm with researchers and healthcare providers to come up with research questions that are important to them. Finally, we discuss how we are going to work together as a research community. This research community is unique. It has to be led by patients or families, not by me or any healthcare provider or researcher, to make sure they have authority and power in terms of the direction they want go.” Chat’s first project enabled

the creation of a patient-centered MS research community in the Midwest (North Dakota, South Dakota, Minnesota, Iowa, and Wisconsin). The second project, currently underway, will use resources developed and implemented in the Midwest project to facilitate the formation of a similar group in the Deep South states (Mississippi and Alabama).



[Diversity in research](#) is another one of Chat's main areas of interest. When research involves a group of people who are too much alike, the findings may not apply to or benefit everyone. It's important for participants in clinical trials to "look like" the patients who could end

up taking the treatments. In Chat's words, "Diversity is critical, especially in pharmaceutical development or treatment development. We know that MS affects underrepresented populations more and differently than the others, but the majority of participants in clinical trials are Caucasian. How can you determine the appropriate treatment and dosing with people who are not in the clinical trial?" From their discussions with participants, Chat and his colleagues have determined that a lack of [trust](#) and accessibility are both barriers to participating in research for minorities with MS. He states, "I spoke to a few patients and they mentioned they don't have access to resources or research. Even if they find a study they still need to be at work. You ask them to participate, spend time with research, but they have two or three shifts of work. How is that going to work?" Chat's study team looks forward to finding solutions for minorities that would like to participate in MS research as they learn more and get a clearer picture of the barriers that stand in the way.

Chat has been instrumental in spreading the word about the researchers who are working with iConquerMS through his monthly webinar series "[Chat with Chat](#)." He shares, "The MS community has given me the opportunity to learn about them and do my research.

This is my way of giving back. We share directly with the community about research that's being done and give them a chance to meet with the researchers, if they want to... We record the webinars and make them available on YouTube." The highlights of being host for Chat include working with the speakers, observing the audience during the webinar and the dialogue afterward. Chat has an exciting lineup of speakers covering a variety of interesting topics in the coming months, including MRI's



and brain scans in MS; insurance, disability income and long-term care; and complementary and alternative medicine. Stay tuned!

Chat states that he initially didn't have a personal connection with MS but as he's been working in the MS space for some time, he now has friends living with MS. When asked how he first heard about ACP, Chat replied, "I never knew about MS until 2015. I was writing a proposal for a project for which I needed to reach out to people with MS. My collaborator suggested that I contact ACP for help. I talked to Hollie Schmidt and she was super welcoming and helpful." When asked what about ACP's mission inspires him the most, he shares, "How they can reach out to people and connect. At every Leadership Summit, every time we create a new meeting, there will always be new people. Some people think I am an extrovert, but I'm really an introvert. So, when I see people that can make or expand a network, that amazes me."

Chat is the first researcher to become an iConquerMS Ambassador. He shares, "This means a million dollars to me. I think I have been an informal ambassador forever. My first collaboration was with iConquerMS. For me, iConquerMS is family, they are very special, almost like my parent organization. Whenever they need help or whenever I feel like I can help them, I would not be reluctant." We appreciate Chat's hard work and dedication to serve the MS community and are honored to have him as a member of the iConquerMS team. Would you like to accelerate MS research through iConquerMS, too? Here are some fun ways to join in!

Join Now

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



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, graphic design or writing? [Volunteer](#) your talents to advance iConquerMS's work!