



Gatherings Around the Country Generate Patient-Centric MS Research Topics

“What questions do you have about multiple sclerosis when you’re preparing to meet with your neurologist and, equally important, what questions occur to you after you’ve left her or his office?” This is the way Dr. Tim Vollmer framed the conversation at a recent gathering held in Denver, Colorado. Called a “Research Studio,” the event brought together 15 people with MS and Dr. Vollmer and his colleague, Dr. Augusto Miravalle, to generate ideas for MS research on the topics that matter most to people who are living with the disease. It was one of four similar meetings held this month across the country; the other three were in Atlanta and San Diego. A total of over 50 people with MS participated.

The Research Studios were organized under the auspices of iConquerMS™ (www.iConquerMS.org), as a way to further the initiative’s goal of empowering people with MS to impact the MS research agenda. They showcased the wisdom of people with MS: those who are recently diagnosed and are literally brimming with questions; those who have lived with the disease for decades; and everyone in between. In each location, neurologists and other clinicians who conduct MS research and who embrace the goal of patient empowerment participated, listening attentively and contributing their own knowledge and expertise to the conversation. In addition to Drs. Vollmer and Miravalle, these included Drs. Ben Thrower, Deborah Backus and Guy Buckle of the Shepherd Center in Atlanta and Dr. Revere “Rip” Kinkel of the University of California San Diego.



A wide range of issues affecting people with MS was discussed at the meetings and from it, a long list of possible research topics emerged. Common themes included studies about possible *causes* such as genetics, viruses and Vitamin D deficiency; *treatments* such as stem cell transplants, medical marijuana and the recently announced ocrelizumab (among many other disease modifying therapies); and the impact of *self-care options* in the areas of exercise, diet and stress management. In several meetings, participants cited the increase over the past decade in the number of African-Americans diagnosed with MS and noted that research on MS in African-Americans is far behind the curve. And speaking of diagnosis, numerous participants expressed the belief that they had MS “for a long time” before being correctly diagnosed with the disease. Said one participant, a 45-year old man with PPMS, “I

believe that I've had MS for most of my life, because I experienced symptoms that are associated with MS from the time I was a child. I just didn't get the proper diagnosis until 10 years ago."

In Atlanta, topics relating to physical therapy, exercise and stress management took center stage, with several participants expressing a desire to push themselves to their maximum capability, in the hope of regaining some portion of the athleticism and the cognitive abilities they possessed before contracting MS. They raised the question of whether it's possible to reverse damage and disability through physical exercise and purposeful mental activity.

In Denver, a participant observed that, "Not all people with MS are motivated to help themselves. How do we reach them?" This precipitated a lively discussion about ways to alter the doctor/patient relationship, so that people with MS are educated and feel empowered to make the best use of their time with their doctor. The same participant who had raised the question asked, "For patients who are new to MS, could another patient serve as their advocate and accompany them to their doctor visits?" He then offered, "I would gladly go along with another patient to help them formulate questions and write down answers for later reflection."

In San Diego, participants picked up this theme, with one woman wondering, "How much of my neurologist's time can I expect?" while acknowledging that she is reluctant to take more than her fair share. Other topics that interested participants in San Diego were the impacts and efficacy of autologous stem-cell transplants and the use of medical marijuana (only legally available in a handful of states).

In the coming month, Accelerated Cure Project staff will produce and make available a report detailing these and the many other ideas that surfaced during the Research Studios. Initially, the report will be shared with the over 2,500 people who currently make up the iConquerMS™ network, with more people joining every day, and the additional people who participated in the Research Studios.

The Research Studios represent just one means by which iConquerMS™ is gathering input from people with MS. Other means include soliciting research ideas from members via the iConquerMS™ portal. While iConquerMS™ is still in the process of developing protocols for reviewing and prioritizing research topics suggested by people with MS, in the coming months we expect these processes to be formalized. For instance, it is likely that a list of the most commonly suggested topics will be posted on the "For Researchers" section of the iConquerMS™ website, to let investigators know the topics in which the patient community is particularly interested.

If you or someone you know has MS and hasn't yet registered with iConquerMS™, we encourage you/them to visit www.iConquerMS.org and register. The process is straightforward and will ensure that you are kept abreast of future action on the topics generated in the Research Studios.

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