

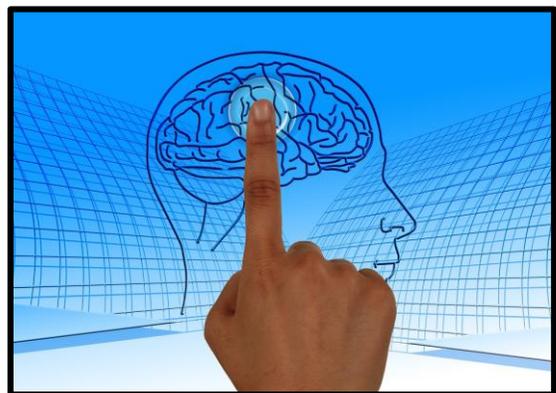


Dear Friends,

This is the first of a new kind of newsletter you'll be receiving from us. In it you'll meet 3 people who are benefiting from our work to accelerate research towards a cure. One is a scientific entrepreneur; the second a patient; the third is the parent of a person with MS. Their stories illustrate the impact your support makes possible. And, in case you missed it, you can listen to a [podcast](#) that aired on our Multiple Sclerosis Discovery Forum, in which noted actor and science advocate, Alan Alda, talks about the art of good science communication.

Blood Samples Illuminate a Window into the Brain

Tucson-Based MSDx is a company that is developing inexpensive, reliable blood tests for monitoring neurodegeneration in brain diseases. These products may provide neurologists with critical data that can be useful in diagnosis, monitoring, and assessing how patients respond to therapeutics for brain diseases such as MS and Parkinson's. The tests could make it possible to obtain important patient information well before a person begins to experience symptoms. In turn, this can help doctors monitor and assess a patient's condition throughout his or her lifetime.



Co-founder Marie Wesselhopf is a bundle of positive energy, a problem solver, a life-long innovator. Before MSDx, she ran the University of Arizona's business incubator. In an example of one innovator attracting another, Marie found her way to Accelerated Cure Project five years ago, when MSDx needed blood samples from people with MS to develop a new blood testing tool. The tip came from a local patient with MS and from a suggestion of Dr. Timothy Volmer, one of ACP's most active and enthusiastic collaborators, who knew about ACP's Repository of biosamples.

Marie describes what happened next. "At the time, we needed fresh cells from newly diagnosed people with a very specific treatment history. We signed an agreement with ACP and soon afterwards, samples that met our specifications were shipped to MSDx for testing. An MS patient would visit one of ACP's cooperating clinics around the country where their blood would be drawn. Then ACP would send some tubes to the Repository for storage,

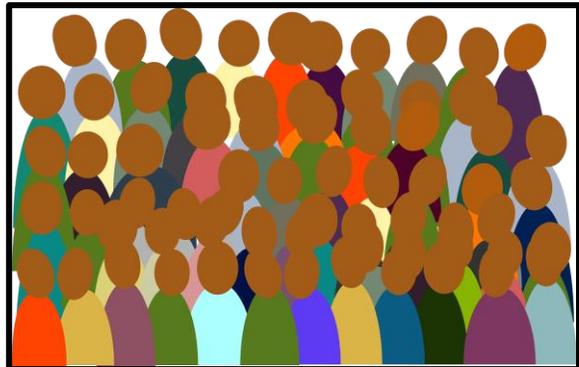
and send a tube to MSDx. We received samples on over 200 MS and other disease subjects. We never could have accomplished this on our own! We couldn't have built the infrastructure necessary to recruit, consent, draw, and process the samples. Without ACP's Repository, it would have cost us \$500 to \$2,000 per sample and taken years to get this number of samples!

“Getting the samples quickly and cost effectively was key to the development of our patented, WINDOW INTO THE BRAIN™.” This test is like a brain biopsy that's non-invasive. It offers a real-time view of pathological processes and disease activity in the brain by utilizing molecules and cells that participate in the mechanism of the disease, as biomarkers for diagnosing the disease. These cells contain important clues about the disease activity taking place in the brain. The MSDx technology measures this biomarker cargo within the peripheral blood PBMCs. MSDx expects that continuing and future research will validate this marker approach for research and clinical use.”

ACP is proud to have played a role in accelerating the development of new diagnostics to extend patient's lives, and lead to a cure.

Patient Power to Conquer MS

Stephanie Butler is a MS certified nurse practitioner, a fitness enthusiast, and an eternal optimist. In 2013, at the age of 25, she was diagnosed with MS during the first year of her nursing education. She recalls the initial symptoms of trouble. “I was running and my right foot fell asleep, only it never woke up again. Then, gradually, over the next couple of weeks, both legs and my right arm also went numb.” At first, Stephanie ignored her symptoms, but they persisted and so finally she checked into the ER. She describes her eventual diagnosis as, “More of a relief than anything; I was emotionally tired of not knowing what was happening.”



Instead of letting that be the end of her story, Stephanie chose to make it the beginning. Within six months she became a Multiple Sclerosis Certified Nurse and began working in the same MS center where she is a patient. She also chose to pursue an advanced degree and just graduated as nurse practitioner, certified in MS. And along the way, she got married. On her blog, www.justkeepsmyelin.com, which was nominated for one of Healthline's best health blogs of 2014, she offers a unique perspective on Multiple Sclerosis as both a healthcare professional and as a person who lives with the disease every day.

One of the many ways that Stephanie aims to take greater control of her future is through her leadership of [iConquerMS](#), Accelerated Cure's new *patient powered research network*. Stephanie's love of science and first-hand experience with the disease, combined with her nursing background, makes her a vital member of this patient governed initiative that amplifies the voice of people with MS and connects them to the research community. In the

new era of consumer-driven healthcare, it's increasingly important that people with MS contribute, not only their data, but also their ideas, their enthusiasm, and their energy, posing research questions that matter to them.

Through [iConquerMS™](#), Stephanie and the initial 2,000 other people living with MS who have registered so far will have the chance to affect the direction of research. They are the heart and soul of iConquerMS™. Unlike other disease-based data-gathering initiatives, patients govern and drive the program. People with MS suggest research topics and questions in areas that matter to them. And they receive updates on what researchers are learning from the collected data. Moreover, iConquerMS™ is not a stand-alone effort. It is part of a national research network called [PCORnet](#) that is enabling collaborative partnerships to improve healthcare and advance medical knowledge in ways never before possible in the United States. Accelerated Cure Project is proud to be working with Stephanie and other big thinkers who are charting the future of biomedical research.

MSDF Turns Knowledge into Power

Susan Rosen describes the period after her 28-year old daughter, Mary, was diagnosed with MS as “my lost year . . . a time when I was literally paralyzed, unable to eat, work or exercise. I am no scientist and all of a sudden, knowing human biology so that I could understand what was happening in Mary’s body was more important to me than anything else in the world. But I couldn’t understand it. I needed somebody to ‘uncomplicate’ the science.”



Looking back on that time, Susan now sees that what was scariest was the unknown—the Big Questions for which she had no answers. What, exactly, is multiple sclerosis? What did this diagnosis mean? What impact would it have on her daughter’s future, including a brilliant career, already launched and well underway? And, most critically for a smart problem solver like Susan, what’s being done to treat and cure this awful disease?

About a year after Mary’s diagnosis, Susan forced herself to begin talking to friends and family members and networking her way to those who could teach her about the science of MS. Upon the advice of a leading geneticist, she read *Multiple Sclerosis: A Comprehensive Text*, by Dr. Henry McFarland, often referred to as “the bible of MS.” One friend, a Ph.D. scientist, introduced her to a leading MS clinician. Susan arrived to that meeting with Mary’s medical file in hand. The clinician slowly and gently walked her through the physician reports, diagnostic test results, and other data it contained.

Soon thereafter, while Googling various MS topics, Susan stumbled across the Multiple Sclerosis Discovery Forum (www.msdiscovery.org), which ACP had just launched. Originally

conceived as a vehicle mostly for scientists, from the start MSDF's clearly written content spanning basic science to clinical research drew a full range of stakeholders. Susan joined a growing community of readers that includes clinicians of all stripes, medical students, bench scientists and a growing community of patients and their loved ones. Now, she logs on every day.

Without dumbing it down, MSDF makes scientific findings understandable and accessible to everyone. Its writers avoid the use of jargon that gets in the way of comprehensibility; they highlight the potential clinical impact of the research and they seek innovative ways to communicate important information to its diverse audience. Susan was hooked, and this addiction has done her good. The more she read, the more she learned and the more she learned, the more courageous she became. Today she says, " Knowledge is power. It has helped to abate my fear and has enabled me to deal with the facts. I understand much better what I can affect and what I cannot change and that, in turn, makes me a better mom to my daughter."

Please tell us what you think of this newsletter format! Have a story you'd like to share, a topic to suggest, a subject to debate? Drop us a line at info@acceleratedcure.org. And while you're at it, why not forward this newsletter to friends, family and colleagues who should know about our work. We look forward to hearing from you.