



REAL MS™: A Platform for Personalized Medicine Research in MS

In June, we reported on [iConquerMS™](#), a 3,000-strong patient-powered research network for people with MS, which Accelerated Cure Project has been building for the past 18 months. This month, iConquerMS™ launched a pathbreaking MS research initiative. Called REAL MS™, the effort will be a longitudinal study of MS. It is intended to answer important questions about the heterogeneity of the experience of MS across the population of people living with the disease and to identify ways to personalize clinical care by identifying factors that affect progression and treatment outcomes. REAL MS™ (Research Engagement About Life with Multiple Sclerosis) will encompass a diverse population of thousands of individuals living with MS, who will participate by answering online questionnaires about their disease experience and by providing biosamples for molecular analysis. For each person living with the disease, REAL MS™ will be a very personal study about them and others like them living with the disease.

REAL MS™ is modeled on the Framingham Heart Study, a longitudinal community-based research study launched in 1948, which has had a profound impact on our understanding of the causes of heart disease and how to treat and prevent it over the past 68 years. REAL MS™ emphasizes identification of personal characteristics and environmental factors that may interact with genetic predispositions to influence outcomes, and the discovery of molecular biomarkers of the disease through genomic and other biochemical profiling. Participation of a diverse population of those living with MS to provide their ideas on research conducted with their information, and a commitment on the part of the iConquerMS™ leadership to promptly and openly share research findings, are important aspects of the REAL MS™ study.



Current MS subtypes (relapsing and progressive) are broadly defined based on the presence or absence of disease relapses. “REAL MS™ may accelerate personalized approaches to MS by making it possible to classify individuals into new subtypes based on comprehensive personal characteristics and laboratory data and then to enable prediction of the likely course of disease based on such subtypes.

The study could also provide people with MS and their physicians with new information on their likely response to particular disease-modifying therapeutics, and facilitate interventions early with treatment strategies to arrest, cure or prevent MS. In these ways, REAL MS™ has the potential to impact both short and long-term. By studying the patterns of many thousands of individuals living with MS, researchers may be able to discern patterns about factors that slow the disease or improve day-to-day functioning. Similarly, by identifying genomic and other biochemical factors, the study might provide biological pathways for new treatments that will arrest, cure or prevent the disease longer-term, including a new understanding of biological mechanisms of progressive MS for which there currently are no approved treatments.

“Those of us living with multiple sclerosis are very excited by the launch of the REAL MS™ study,” noted Laura Kolaczowski, Lead Patient Representative and Co-Principal Investigator of iConquerMS™. “We see it as the first-ever opportunity for active involvement of participants in determining which research questions will be studied and how research protocols are designed. Those of us who live with MS now have a voice in research, and if as a result, new knowledge emerges to guide our treatment choices based on individual characteristics, the impact will be tremendous.”

Qualified researchers will be able to access the REAL MS™ dataset for their ongoing or new studies about causes and progression of MS. They will also have the opportunity to conduct special data collection activities via iConquerMS™ for specific research studies; to collect biosamples and conduct genomic and other biochemical analyses; and to seek individuals with certain characteristics for their research studies or clinical trials of targeted treatments. However, because REAL MS™ is not a study of a particular drug, FDA approval of the study design was not needed. Instead, REAL MS™ has been reviewed and approved by an IRB (that is, an Institutional Review Board), a special body that ensures that research subjects will not be exposed to unethical research practices.

In the coming months, we will be sharing more information and news about REAL MS™. In the meantime, to get started you must join iConquerMS™ by reviewing and signing a consent form located at www.iConquerMS.org/join. You will be asked to fill in detailed questionnaires online twice each year about your personal characteristics and background, your health history and your experience with multiple sclerosis.