

Sharing health information may yield solutions for MS



by **Marcella Durand**

When it comes to understanding multiple sclerosis, the more data that researchers have, the better. By looking at health information provided by thousands of people living with MS, researchers may be able to uncover patterns and gain greater insights into the disease—including possible causes, treatments and ways to manage MS for improved quality of life.

To that end, individuals can participate directly in MS research and help shape its direction through a new nonprofit, patient-centered initiative called iConquerMS. The program asks people living with MS to share their electronic health records, with hopes that researchers may be able to answer such questions as: Which treatments work best in which people? How helpful are diet and exercise in reducing the impact of MS? And is it possible to predict the course of MS based on others' experiences?

To make iConquerMS most effective, organizers are hoping to involve at least 20,000 individuals with MS from a range of ethnicities, ages and disease stages. Participants will be asked to share their electronic health records via an online portal at iConquerMS.org. In turn, those who upload their records will receive regular research updates, progress reports and alerts to new surveys. Additionally, participants will be invited to suggest MS research topics of particular interest to them.

Understandably, some people may have questions about how the health records they share will be kept private and safe. To address these concerns, iConquerMS is encrypting uploaded health records and removing all identifying information before sharing any health data with

researchers.

The iConquer MS initiative is part of a research network that links patients and researchers nationwide at the Patient- Centered Outcomes Research Institute (PCORI). Leading MS organizations, including the National MS Society, are providing support to iConquerMS, which was created through a partnership between the Accelerated Cure Project for MS, Feinstein Kean Healthcare and Arizona State University.

To learn more or enroll in the program, visit iConquerMS.org.

To learn about other research opportunities, visit nationalMSSociety.org/Research/Participate.