May 2020 Newsletter

Using Data to Combat COVID-19

In recent months, researchers have been hard at work trying to understand the nature of the new coronavirus (COVID-19), its impact, why it affects some people more than others, how to reduce or prevent its spread, as well as effective ways to diagnose, prevent, and treat it. Data and analytics are vital to these efforts.

iConquerMS is an important tool for obtaining the necessary data to understand the full scope of how COVID-19 affects those affected by MS. By mobilizing this expansive network and collecting real-time data from its members, ACP is leading the way in efforts to help people affected by MS and their doctors during the current pandemic and in the event a future viral outbreak should occur. These data hold great potential in helping clinicians identify the best way to manage the new coronavirus in people with MS and informing individuals about how to achieve the best outcomes.

iConquerMS is a powerful resource for MS research that is unique in a number of ways. A primary objective of the initiative is to enable all people affected by MS to participate in research. Network members can not only contribute data about their MS experience by completing online surveys,

but also steer the direction of research by contributing their ideas for future studies. In other words, the network is centered on research driven by people affected by MS into topics that are both relevant and important to them. It is a nonprofit endeavor governed by people living with MS, therefore governance and research decisions are based on what is in their best interests.

In early April, ACP, together with researchers at Massachusetts General Hospital, launched a first-of-its-kind survey through iConquerMS to understand how individuals affected by MS are coping with the current pandemic and what their personal experience has been throughout. Network members are providing information about changes or delays in MS treatment due to COVID-19, as well as its impacts on quality of life, including employment, finances, and wellness. The survey also includes questions about where people with MS are obtaining information about COVID-19, their current level of understanding of the virus, and what they are doing to lower the risk of exposure or transmission. For those who have been potentially exposed or have experienced symptoms, the survey tallies who has been tested and/or treated for COVID-19.

Over one thousand people from 24 countries have completed the COVID-19 survey to date, 98% of whom have been diagnosed with MS. The majority (88%) of respondents live in the United States. Preliminary results show 47 individuals were tested for the new coronavirus (9 tested positive) and 145 wanted to be tested but hadn't been because the test was either not available, not offered by the individual's doctor, or they didn't meet the criteria for testing. Many people had medical visits or tests postponed or cancelled due to COVID-19 (22% of neurologist appointments, 21% of lab tests, 11% of MRI's, and 48% of other medical visits were affected). Those completing the survey also reported difficulties or delays in accessing their healthcare (18% had problems getting medical procedures performed, 17% had trouble accessing complementary/alternative medical services, and 11% had an issue concerning their disease-modifying therapies). Of note, 36% of respondents had healthcare visits performed via telehealth as a result of the pandemic. Data revealed the coronavirus and public health response have moderately impacted people's ability to

exercise, their financial situation and their diet/access to food. Responses also revealed that people are experiencing stress, anxiety, boredom, and isolation during the current pandemic. This survey will be readministered to see how responses change over time.

To the extent possible, survey questions and data fields have been aligned with data collection initiatives of other MS organizations. Results will be de-identified and shared with an international initiative, created by the Multiple Sclerosis International Federation and the MS Data Alliance, which is gathering data from healthcare providers and people with MS across the world. Pooling COVID-19 data from each organization together will advance research into the virus and its impact on MS patients globally. In addition, qualified researchers can request data from iConquerMS for the purpose of conducting their own studies. In this way, data collected by the iConquerMS COVID-19 survey could assist researchers in developing diagnostics, drug treatments, vaccines and other approaches to managing COVID-19 in the context of MS.

Interested in taking the COVID-19 survey?

We're still collecting insights from people affected by MS (with or without a diagnosis) via the COVID-19 study. You do not need to have exhibited symptoms or have been tested for or diagnosed with COVID-19 to participate.

If you're already an iConquerMS member, just log in to your account. You'll see a new survey called "COVID-19 Survey" in your list of research surveys.

If you're new to iConquerMS, click "Join Now" on our home page to become a member of iConquerMS. You'll be asked to provide your email address on the sign-up page, and then you'll receive an email with a log-in link. Click this link to come back to iConquerMS and set up your password and profile.

Once your account is created, you'll see a list of surveys. Click on "COVID-19 Survey" to get started. Because this is your first iConquerMS survey, you'll be presented with a consent form to read and accept before taking the survey.

Until recently, there is no reporting system organized in North America to collect data that can track the outcomes and potentially inform treatment of people with MS infected

with the new coronavirus. The Consortium of Multiple Sclerosis Centers and the National MS Society are collaborating to create COViMS (COVID-19 Infections in MS & Related Diseases), a newly launched North American database for healthcare

professionals to capture de-identified data related to COVID-19 infections in people with MS and other demyelinating diseases. Medical professionals who are caring for patients with these conditions, and who have confirmed or suspected COVID-19 cases, are encouraged to use the database to report outcomes. The goal of this research is to determine the impact of the new coronavirus on MS and associated disorders, and to learn how factors such as age, comorbidities, and treatments affect COVID-19 outcomes. For those interested, data from this registry will be shared directly on the COViMS website, through electronic mailing lists/social media, and via scholarly publications.

We, at ACP, believe that research is the only way to greatly improve the outlook for people with MS. Our organization works to promote scientific collaboration and accelerate research by providing researchers with data and biospecimens they need to conduct research that can lead to better care and outcomes for people with MS. The unprecedented impact of coronavirus around the world has sparked the need for powerful partnerships to work together to fully understand the impact of COVID-19 on people living with MS, and in general, as well as determine the most effective ways to prevent, treat and ultimately cure this illness. ACP has been a leader in these research efforts by being the first to collect valuable patient-reported outcome data from iConquerMS network members relating to their experience with COVID-19 and sharing this information with other MS organizations and researchers who are working toward this goal. Collaborations such as these will significantly contribute to finding viable solutions and the best outcomes for all.