Repository Spotlight – The Power of Data

ACP is dedicated to facilitating research to improve diagnosis, to optimize treatment and to cure MS. Real-life patient data plays a pivotal role in our work. Collecting this vital information has been key to achieving ACP’s mission since its inception. The organization’s first large project was the collection of blood samples from people with MS, their relatives and unrelated controls, along with detailed clinical and other phenotypic data (the ACP Repository). These samples have been made available to over 100 investigators with the stipulation that their research data must be returned to ACP. Some of these studies have been highlighted in previous newsletters. We now have a growing collection of returned research data that is also available to investigators for further research and analysis. This large amount of returned data is an important resource for the discovery of MS drug targets and disease biomarkers, however it presents a logistical challenge with regard to storage and access. In the fall of 2017, we signed an agreement with BC Platforms to store and curate the patient clinical phenotype data as well as the returned research data. This will allow ACP and its research partners to more easily access this valuable information resource.

iConquerMS has expanded our data focus from the clinical sites used for the collection of Repository samples into the patients’ living rooms. This initiative has added an important data category – patient reported outcomes (PROs). As ACP moves forward, we will continue to make these anonymized data available to investigators. In addition, we are planning a new, updated Repository collection that will allow us to collect new data, along with blood samples, and to integrate a broad range of important data categories. Stay tuned!