



## Visualizing the Future of MS Research: ACP's Repository Holds the Map

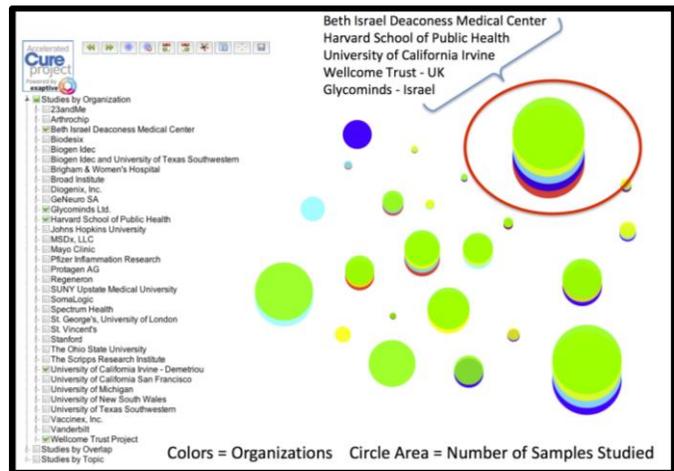
When Accelerated Cure Project's Repository of biosamples and data was launched 10 years ago, it was modeled on the Open Source movement of the 1980's and 90's, which had dramatically accelerated the growth of the software industry. For those who don't remember it, Open Source was a worldwide movement that enlisted the cooperation of software programmers to produce high-quality programs by sharing their work with other like-minded people around the globe. If scientists could be similarly enticed to share biomedical research outcomes and data, the thought was, they could speed up the process of discovery.

The 3200+ people who contributed samples and data (perhaps you are one of them!) all knew that they were helping researchers conduct studies into the causes, mechanisms, and treatment of MS and other diseases. What they (you) might not have known is that they were adding to what has since become the largest and most diverse collection of data about multiple sclerosis *in the world*. No other data set that combines biosample analyses, patient reported information and clinical data exists to rival what together we have built. As a consequence, its potential to help unlock the secrets of multiple sclerosis—mechanisms, causes, treatments and cures—is unparalleled.

But, as the song says, "we've only just begun." In order to proactively *drive* biomedical research, ACP has the opportunity to identify the most promising directions and discoveries being made, and to ensure that scientists are aware of them. Our challenge is to analyze this data in order to seek consistent patterns and systematic relationships between variables. In effect this will constitute a "virtual collaboration" between scientists who have used our biosamples and returned data to our Repository. Our objective in this deeper analysis of the returned data is to point the way to the most fruitful scientific inquiries of the future, and to encourage communication between the scientists who have used the repository.



So how does one begin these tasks? What are the first steps in taking a massive, and potentially rich, trove of data and understanding it? To help, we enlisted the assistance of Exaptive, a Cambridge-based start-up that has invented a set of visualization tools for exploring, manipulating, and deriving insights from large quantities of data. Here's what a representative Exaptive "snapshot" of a virtual collaboration among researchers who have used our Repository samples looks like:



At first glance, it appears to be a stack of different-colored disks. But examine it and you will see that researchers from 2 universities--one East Coast and one West Coast, a teaching hospital, an Israeli biotech company, and a British medical research foundation have all studied and analyzed biosamples from the same participants in our Repository! In fact, these scenarios are actually quite common. In many cases, one group of researchers has no idea that other researchers have analyzed biosamples from the same group of individuals, because in the normal course of business, they don't communicate with each other. If the scientists are from different disciplines, one can pretty much assume that they attend different meetings, read different publications and experience very little, if any, cross-fertilization of ideas. ACP aims to change that, by proactively connecting scientists and clinicians whose work overlaps, through off- and online communications.

In addition to the collaboration with Exaptive to better understand what treasure might lie within the Repository data, we are seeking funding to add two full-time professional staff to ACP's current team of 7, to do the work of organizing, analyzing and consolidating our understanding of the data in our possession, while continuing to control access to data and intellectual property to ensure that they are widely available.

Meanwhile, we are taking steps to add new samples to the Repository and making them available to new groups of scientists for innovative research. In the past year, ACP has launched two programs, each of which will enable us to collect large numbers of additional clinical samples from people with MS and continue building the Repository and database.

- [iConquerMS™](#) is a patient-powered research network, expected to eventually number 20,000 people with MS. Registrants are contributing not only their health data but they are driving and shaping MS research through the contribution of research topic ideas. With the network firmly established and growing in numbers, we are about to initiate remote biosample collection to complement the participant's data.
- [The Optimizing Treatment - Understanding Progression](#) (or OPT-UP) Clinical Study is a longitudinal study designed to generate robust evidence to guide the choice of the optimal MS treatment for each individual patient, to generate new knowledge about progressive MS. This initiative will also add valuable longitudinal biosamples and data from thousands of people with MS to ACP's Repository. These will enable investigators to correlate disease progression and drug treatment with underlying changes in patient biology.

Combined, the two programs will result in exponential growth in the quantity and variety of information in our database. Meanwhile, the number of scientists in universities, private companies and laboratories around the world who are interested in receiving and analyzing Repository samples and data is growing daily.

Every segment of the research continuum—from the laboratory to the market—can face scientific and technical obstacles. ACP thinks and acts strategically along the entire continuum, identifying where the science or the technology is lagging behind because of one or many factors. Understanding our Repository data will enable us to accelerate research efforts worldwide to identify new drug and diagnostic targets, to improve the utility of disease models and research tools, and to work with the research community to better understand and treat multiple sclerosis. While it would be great to identify the next “home run,” it is equally important to focus on the types of incremental improvements that will move the field forward, whether investing in tissue banks, databases, patient registries or research platforms. In the process, we expect to promote the realignment of incentives across academic, industry, and public interests around the overall goal of accelerating the development of treatments and cures for this most challenging disease.