



Dear Friends,

This issue is all about Big Data to Knowledge, otherwise known as BD2K. This refers to society's growing ability to gather a wealth of information about people—in our case, people with MS—and to use it to advance our understanding of human health and disease. But while medicine has come a very long way in the past decade, researchers still struggle to get access to the specimens and data from large numbers of human subjects that are the lifeblood of scientific discovery. Listen to a [podcast](#) of noted neurologist Revere “Rip” Kinkel describing ways to effectively engage patients.

For over a decade, ACP has met the need for specimens and data through our Repository. In this issue read about the launch of iConquerMS™, a program through which we aim to collect much more data from an additional 20,000 people with MS, and make the data available for research projects exploring *questions of interest to the community*. And to ensure that data in fact leads to knowledge, learn about our efforts to partner with external experts in bioinformatics and to build our internal capability for large-scale analytics.

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## 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.

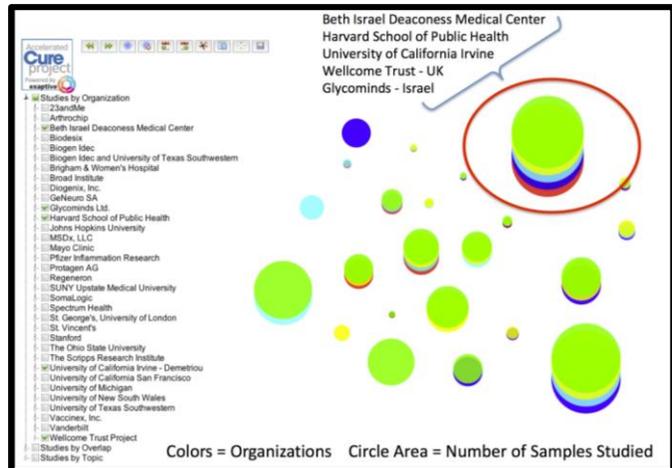


The 3200+ people who contributed samples and data (perhaps you are one of them!) all knew that they were helping researchers conduct studies into the causes, mechanisms, and treatment of MS and other diseases. What they (you) might not have known is that they were adding to what has since become the 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.

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## Healthcare and Life Sciences in the Year 2020: Mechanisms for Patient Empowerment

A lot has changed since our founding in 2001, in medicine and in other fields that influence medicine. The mapping of the human genome; the passage of the Affordable Care Act; stem cell research; and, the growth of targeted therapies tailored to specific patients are just a few of the significant developments that come to mind. Add to these the invention of Facebook and Twitter (we know, it's hard to believe that neither of these existed 14 years ago); the ascendance of Google and Wikipedia; and, our ability to find patterns in millions of pieces of data streaming in from different sources (Big Data), to infer everything from likely romantic partners to the probability of contracting disease.



ACP's success in accelerating the discovery of a cure for MS depends on our ability to understand *and anticipate* future changes in healthcare and biomedicine—to stay ahead of the curve. To that end, we recently turned our attention to a provocative new report from global consulting giant Deloitte, titled, “Healthcare and Life Sciences Predictions 2020.” And, while the report contained plenty of ideas that challenged and inspired us, we were also pleased to discover that ACP's programs *already* track several important future trends that Deloitte identifies. For example, the report predicts that:

*“Informed and demanding health consumers will be active partners with providers in their own healthcare. Online patient communities will have grown exponentially and will be rich sources of crowd-sourced data, with rating systems for drugs and healthcare provision.”*

Launched in the fall of 2014, ACP's Patient-Powered Research Network, iConquerMS™, is already making this description a reality for thousands of people with MS. Social media has played an important role in building the iConquerMS™ patient community, reflecting Deloitte's unsurprising prediction about modes of communication and social organizing in the future. Deloitte also goes a step beyond this in anticipating widespread utilization of social media by healthcare organizations:

*“Healthcare organizations will engage with patients through social media, regularly gauging their needs and driving them to appropriate products and services for their budget and healthcare requirements.”*

Some may regard this as a dream, others a nightmare. Still, there's no question that healthcare providers are preparing to embrace the use of social media in the near future. A few already have. At the launch of iConquerMS™ last year, Dr. Farris Timimi, a cardiologist from Mayo Clinic, described Mayo's establishment of a Center for Social Media to coordinate and focus Mayo's various social media initiatives and programs. The Center employs 7 professionals full time. Mayo wants patients to become better advocates for their own care by using social media tools to get the best information, connect with providers and with each other, and inspire healthy choices.

*“Big data will be pervasive—requiring new tools and provider models. New data driven competitors will disrupt the research & development model with a focus on data and outcomes, as opposed to the science only.”*

The requirement that the many scientists who use patient biosamples from our Repository return their results to ACP's Repository database is generating, dataset by dataset, truly Big Data on the MS patient population. Dr. Raji Balasubramanian of UMass Medical Center in Worcester and Dr. Ken Buetow of Arizona State University are already in the process of analyzing the ACP data, using new tools developed for Big Data analyses. These collaborations are just a start for ACP in extracting new discoveries from a growing database that includes extensive patient clinical information and data that has been returned from investigators who have used the ACP patient samples. With our focus on finding a cure, ACP is poised to play exactly the role Deloitte predicts will be in demand.

*“In 2020, research and development (R&D) will have few boundaries; the R&D model will be networked, built around academic and other partnerships. The share of ‘in-house only’ discoveries will be at an all-time low. Networked R&D will combine pharmaceuticals and technology with increased patient engagement to prevent and treat disease.”*

In other words, the healthcare and life sciences industries will have embraced the Open Source model upon which ACP was built, and will openly share their discoveries. And while that may not yet be true across the board, we believe it will be soon. In the meantime, the rules of ACP’s Repository, that require sharing of outcomes and data, serve to break down barriers and create virtual collaborations among researchers.

We have peered into the future and discovered that our efforts over the past decade have been well in advance of what Deloitte envisions happening by 2020.

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Have a story you’d like to share, a topic to suggest, a subject to debate? Drop us a line at [info@acceleratedcure.org](mailto:info@acceleratedcure.org). And while you’re at it, why not forward this newsletter to friends, family and colleagues who should know about our work. We look forward to hearing from you.