We are excited to announce the launch of www.iConquerMS.org, the website behind our new patient-powered research network! We invite you to join the iConquerMS™ community and contribute your health information for research.

With the participation of thousands of people living with multiple sclerosis, iConquerMS™ will make large amounts of data available to researchers, allowing them to gain new insights and leading to better diagnoses, improved treatments, and ultimately, cures. iConquerMS™ also serves as a bridge to the research community and prioritizes patient contributions to the initiative’s research agenda.

Since our last update, iConquerMS™ has been picking up steam and the project team, consisting of ACP, Feinstein Kean Healthcare, and Arizona State University, has been working tirelessly toward this launch. Input from people living with MS has been gathered at many points along the way and continued feedback on the website and the initiative is welcome and encouraged.

We’ve also convened meetings of the initiative’s Governing Board and Research, Communications, and Membership Committees, leading to enthusiastic conversations around patient engagement, communications efforts, research topics, and other key ideas. The majority of the members of these governing bodies are people living with MS, ensuring that this effort remains truly patient-driven. These groups will come together on December 6 in Boston, MA, Continued on page 3.
Dear Supporters and Friends of ACP,

Congratulations for supporting an organization that is transforming the landscape of MS research.

Since our Spring 2014 newsletter, ACP has launched two major initiatives that promise to revolutionize the treatment of people living with MS and provide a new way for people with MS, their families, friends and caregivers to initiate and contribute to research on topics that matter most to them.

In previous newsletters, we have written about the development of the Optimizing Treatment-Understanding Progression, or OPT-UP, Clinical Study. On September 10th, we announced that EMD Serono had provided the $1 million needed to launch OPT-UP. We are now firmly on the road to discovering why some people benefit from treatment with certain MS medicines while others don’t, and to identifying the key differences between relapsing and progressive forms of MS. We are working with our sites and vendors to get everything in place and expect to begin enrolling participants in the spring of 2015. Please be sure to read an article about OPT-UP by ACP’s own Hollie Schmidt on page 7 of this newsletter, describing the study and asking for your feedback.

We are grateful to EMD Serono for its vision and support of our work. The company has repeatedly supported pioneering efforts in the field of MS, such as providing early support for Fast Forward, a National Multiple Sclerosis Society initiative and enabling the creation of ACP’s MS Discovery Forum, www.msdiscovery.org.

Still, OPT-UP needs millions of dollars more to cover the cost of enrolling and following 2,500 people with MS over a 5-year timeframe. We are seeking funding from other biopharmaceutical companies that market MS medicines, as well as from medical testing and device manufacturers, foundations, and individuals.

A second important milestone was reached on November 17th, with the launch of our new “patient-powered” research portal, www.iConquerMS.org. In our last Newsletter, I wrote about our receipt of funding from the Patient-Centered Outcomes Research Institute (PCORI) to create an online community of 20,000 people with MS for patient-powered research. Thanks to the efforts of a highly collaborative team, the iConquerMS™ initiative has become a reality in record time. Read more about this exciting new initiative in an article by Kirsten Bermingham that starts on page 1.

As always, we continue to build awareness and support for our cause through fundraising events. Check out the fun photos in the middle of the newsletter.

We are grateful for the many ways our supporters contribute to accelerating research efforts to improve diagnosis, optimize treatment and cure MS. As our efforts expand in scope and complexity, so does our need for financial support. Please send your donation to ACP today. We are making a difference!

Thank you so much for your continued support.

With best wishes,

Robert N. McBurney
President & CEO
iConquerMS.org Launches

Continued from cover.

for the iConquerMS™ Leadership summit, made possible by support from Biogen Idec. This event, the group’s first face-to-face meeting, will set in motion iConquerMS™ recruitment and communications efforts and take steps toward identifying opportunities for highly-important, patient-powered research using the network.

People with MS, along with their friends and loved ones, are invited to visit www.iConquerMS.org to learn more. Those interested in participating may register to safely and securely contribute their health information by completing surveys and uploading electronic health records. Participants can also share their ideas on research topics. In late December you’ll be able to participate in online forums and connect with other members of iConquerMS™.

Funded by the Patient-Centered Outcomes Research Institute, or PCORI, which is a non-government organization established by Congress as part of the Patient Protection and Affordable Care Act of 2010, iConquerMS™ is one of the 29 networks that make up PCORnet, a national research network that brings together patient data to enable research never before possible. Our involvement in PCORnet is a tremendous benefit to MS researchers, who can access iConquerMS™ data along with the data from millions of other people enrolled in PCORnet networks. In return, the health information provided by iConquerMS™ participants will benefit medical research in other areas.

Please take a moment to visit iConquerMS.org, join the initiative, and help build this important movement! Your participation is essential in accelerating MS research.

If you have questions about iConquerMS™ or would like to learn more, please contact Sara Loud at sloud@acceleratedcure.org.

Volunteer Spotlight: Eliza Duddy

When did you learn about ACP, and why did you get involved?
I learned about ACP through my mother, who has MS. She heard about the annual cocktail party so we went. We heard then CEO, Art Mellor, explain the repository project and immediately got on the waiting list to be subjects. My brother, mother, and I are all subjects.

Why did you decide to start the Fieldhouse 5K for ACP?
I work for FIELDHOUSE Sports Performance, in the FIELDHOUSE sports complex in Sudbury, MA. We wanted to host a community wellness event to spread the message (the message is self-care and health!). We wanted to support a charity at the same time. I had previously fundraised for ACP (for the Falmouth Road Race) and knew I wanted to support them again. I contacted Lindsey Santiago who was a tremendous help throughout the entire process. I’d never coordinated a 5k before, let alone as a fundraiser!

What was your favorite moment from the 5K?
The start/finish line. A daughter of one of my client’s sang the national anthem, and the quiet that surrounded the start of the race (and the excitement that immediately followed) really culminated the entire event for me. Months of planning for the 30ish minutes that people ran. When those 100+ runners crossed the starting line, I was elated.

What do you see for the 5K next year? More runners! And more funds raised.

What do you feel sets ACP’s mission apart? The interdisciplinary research the ACP supports is unequalled. Without their efforts, MS research is too disconnected.

What might someone be surprised to know about you? hobbies? Not surprising at all, I am a runner. Besides the Falmouth Road Race, I just competed in my first marathon in Chicago. Surprising? I spent half of the last year living (and running) in the Azores, Portugal.
Sights and Sounds on the MS Discovery Forum

In our last newsletter we featured the first in MSDF’s new series of MS data visualizations. Data visualizations allow large sets of numbers to be explored in new ways, making it easy to see unexpected relationships in clinical and scientific information. We are grateful to Genzyme, which has provided generous grants to fund both our data visualizations and our podcasts.

Since that first interactive bubble chart, we’ve published six more visualizations at a rate of about one each month. One of the most interesting collates information from more than 25,000 people with MS who were followed for up to 30 years. It shows how measures of 11 different symptoms (including mobility, fatigue, and depression) tend to get better or worse over decades.

In another visualization, Dr. Suhayl Dhib-Jalbut, who has a deep knowledge of MS immunology, clearly explains the convoluted immune-system pathways involved in MS, unpacking them step by step.

We’ve also started a weekly podcast: “Multiple Sclerosis Discovery: The Podcast of the MS Discovery Forum.” Each weekly 15–20-minute episode includes the latest in MS-related research news along with an extended interview with leading MS researchers and clinicians. You may listen to the podcasts at http://msdiscovery.org/podcasts, or you can download them from iTunes or from your favorite podcast app.

At this writing we’ve posted 20 podcast interviews, including Dr. Gavin Giovannoni on the Epstein–Barr virus and on finding a cure for MS, Dr. Alan Thompson on research on progressive MS, and Dr. Wendy Macklin on what zebrafish are teaching us about MS. We post a new episode every Monday.

Another research resource is our “Drug-Development Pipeline,” a detailed and continuously updated database of (at present) 43 investigational agents under study for MS, with new agents being added at a rate of one per month. You won’t find more detailed, up-to-date, freely available information on the contents of the MS drug pipeline anywhere.

And, of course we’re especially proud of our “News and Future Directions” section, which contains articles by medical and science journalists who are highly experienced in following the trends and developments in MS research. Recent months have seen numerous articles on progressive MS, the result, in part, of a generous grant from the National Multiple Sclerosis Society.

We’ve also published articles on ways to track remyelination; on how deep-brain stimulation is helping some people with MS control their tremors; and what research tells us about how women with MS and their physicians should deal with pregnancy, childbirth, and breastfeeding.

While MSDF is intended primarily for physicians and scientists, we aim to make everything on the site accessible to anyone with a deep interest in MS. We welcome your visits—and your comments at www.msdiscovery.org.

Don’t miss Dr. Wendy Macklin’s recent MS Discovery podcast on what zebrafish are teaching us about MS.
Thank you to the wonderful volunteers, donors and sponsors for Accelerated Cure Project for MS events.

This was definitely a year where “Miles for MS” could have been our slogan. Our volunteers truly went the extra mile and so many others racked up miles to support ACP on foot, on the road, and on the water.

We would like to thank all of the volunteers, participants, supporters, and donors for helping ACP and making a difference. Thank you again.
Many of you reading this newsletter were first introduced to Accelerated Cure Project when someone at your MS clinic invited you to donate blood samples and data to a repository that would support research all over the world. We’re delighted to give you an update on this resource and describe how your samples and data have been used—and continue to be used.

The ACP Repository includes samples and data from 3,236 people who enrolled in the study at 10 sites located across the US. There are nearly 1,900 people with MS or a single attack; around 600 with other diseases, many of whom were enrolled with the support of the Guthy-Jackson Charitable Foundation and the Transverse Myelitis Association; and over 700 control participants. Blood samples have been processed into subsamples of DNA, RNA, serum, plasma, and immune cells and are kept in long-term frozen storage at a lab in Maryland. Each participant provided extensive information about their health history, past and present treatments, race and ethnicity, family disease history, symptoms, and many other topics. All of this information is stored in an electronic database for scientific analysis.

The ACP Repository is a truly open-access resource, meaning that scientists from any institution anywhere in the world are encouraged to request samples and data to use in their studies. So far we’ve approved 82 requests with more being submitted every year. Researchers have used the Repository to study topics such as:

- Finding genes that affect the risk of MS and neuromyelitis optica (NMO)
- Exploring factors such as stress, trauma, or vaccinations that might trigger disease activity in MS, NMO and transverse myelitis
- Developing a blood-based test that can quickly and easily diagnose MS
- Testing the potential efficacy of a developmental therapy for NMO
- Understanding the role of Epstein Barr virus in MS

Most of these requests (55 out of 82) came from academic or government researchers, while 27 were submitted by companies, mainly in the pharmaceutical/biotech industry. We’ve sent samples and data across the globe to support 15 international studies based in Australia, Israel, Germany, and elsewhere. Projects range in size from small pilot studies to the large-scale collaborations of the International MS Genetics Consortium, in which ACP Repository samples have been analyzed along with tens of thousands of others.

An important feature of the ACP Repository is that researchers must promise to send us their data after they’ve performed their experiments. We now have data sets from 33 different studies containing nearly 700 million data points (with many more to come!). We’re currently working to organize this data and promote it within the research community so that others can make use of it to generate new findings about MS.

Many thanks to all of you who have made the ACP Repository such a valuable resource by donating your blood and your information! We invite everyone who would like to learn more about the ACP Repository, and the studies that have been enabled by it, to visit our website at http://www.acceleratedcure.org/impact/repository. You can also visit http://tinyurl.com/acp-studies to download a spreadsheet describing the studies.
In October 2011, we brought the neurologists from our ACP Repository sites to Boston to discuss forming a research network that would address important needs in MS. As we talked about what this network might focus on, two issues rose to the top of the priority list as being extremely frustrating for patients and clinicians alike:

1. People with relapsing MS must often try many different treatments before they find one that decreases their disease activity without too many adverse effects or safety risks. They may cycle through 3, 4, or more MS therapies in their search for the “right drug,” wasting time and money while experiencing continued relapse activity in the process.

2. The currently available MS drugs have been demonstrated to prevent relapses but not to prevent or slow progressive MS, leaving many people with MS without proven treatment options. Not enough is known about what causes progressive MS and therefore therapy development is lagging.

Since that meeting, the ACP Clinical Research Network has been working to develop a study that would address both of those critical issues. We are now on the verge of launching this study which we’ve named OPT-UP, for Optimizing Treatment—Understanding Progression.

OPT-UP will enroll a cohort of 2,500 subjects and follow them for up to 5 years, collecting a wealth of data about their response to treatment, MS symptoms, functional test scores, MRI measurements, biomarker characteristics, and much more. All of this data will be analyzed by the network members and shared with partner organizations to (1) understand which people respond best to which treatments, and (2) identify factors that either promote or slow/prevent progressive MS.

Our goal is that in 5 to 10 years, results from OPT-UP will enable individuals with MS to work with their clinicians to determine which therapies are most likely to be effective and safe, specifically for them, without repeated trial and error. In addition, OPT-UP’s findings will inform people with MS about what they can do now to prevent or slow progressive MS and will also give pharmaceutical companies the information they need to invest in developing new drugs tailored to progressive MS.

With start-up funding in place from EMD Serono (see our CEO’s letter on page 2), we are working with our vendors to put the study systems and procedures in place. We’re also coordinating with our MS clinical sites to get them ready to start enrolling subjects in the spring of 2015.

Throughout the OPT-UP development process, the voice of people with MS has been well-represented by the members of our Community Advisory Panel, who have contributed to the design of OPT-UP and will continue their involvement through study launch and beyond. But we would like to hear YOUR voice as well:

Have you had trouble finding an MS drug that is safe, effective, and free of troublesome side effects? Have you been down the trial and error path more than once? Do you have progressive MS and wish that more help was available, or are you concerned about developing progressive MS in the future?

Please let us know on our Facebook page, via Twitter, or by email to hollie@acceleratedcure.org.
Welcome Cynthia McKelvey

We welcome Cynthia McKelvey, staff writer for the Multiple Sclerosis Discovery Forum and the newest member of the ACP team. She began as a summer intern at MSDF and was hired fulltime in October. Cynthia is a graduate of the Science Communication graduate program at the University of California, Santa Cruz. Thoughtful, in-depth science reporting is Cynthia’s first priority as a journalist, and she is excited to bring those skills to the world of MS research. She lives and writes from her home in Berkeley, California. In her spare time, she enjoys cooking, rock climbing, and visiting museums.

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