World MS Day is May 28. Established by the Multiple Sclerosis International Federation in 2009, it is the only global awareness raising campaign for MS.

Since its inception, World MS Day has reached hundreds of thousands of people in more than 67 countries worldwide.

ACP strongly supports a coordinated worldwide effort to cure MS. We are enthusiastic about working closely with other organizations to fight this disease. We greatly value our participation in the MS Coalition, a group of 8 MS-focused organizations in the US (ms-coalition.org). United we stand!

To find out more about World MS Day, visit www.worldmsday.org.
Dear Supporters and Friends of ACP,

Your support makes great things happen.

Since our Fall 2013 newsletter, ACP has been awarded $1 million to create a new online community of 20,000 people with MS to accelerate research!! This online MS community is called the MS Patient-Powered Research Network (MS-PPRN). The MS-PPRN will participate in a new, revolutionary, national network for clinical research.

Our “little engine that could” has received national recognition of its efforts to accelerate research to cure MS. A key reason that ACP received this award is our success in establishing the open-access ACP Repository involving 3,200 participants (many of you) that has supplied biological samples and data for over 70 investigations to 59 research groups worldwide. Without your support to build the Repository, we could not have reached this important milestone for people with MS and the MS research community.

The award was made in December of last year by the Patient-Centered Outcomes Research Institute, or PCORI (www.pcori.org) – a non-profit organization created by the Patient Protection and Affordable Care Act of 2010. Considering all the discussion about the Affordable Care Act, it is a little surprising that few people know about PCORI and its mission to transform healthcare by helping people make informed healthcare decisions; by improving healthcare delivery and outcomes; and by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers and the broader healthcare community. It seems that good news is no news.

The MS-PPRN is one of 18 funded patient-powered research networks, each focused on a different disease or disorder, that will be linked together with 11 clinical data research networks, mostly multiple hospital systems, into a national network that will involve up to 100 million people in the US. Although our MS-PPRN will involve 20,000 people with MS directly, through the network we will have the opportunity to involve up to 100,000 people with MS to raise research questions that matter to them and gather data and biological samples to answer those questions. MS-PPRN will complement the in-clinic assessments, MRIs and patient-reported outcomes of the OPT-UP Clinical Study that we plan to launch in early 2015. There is a brief description of the OPT-UP Clinical Study later in the newsletter.

We are currently working vigorously with our partners, the Complex Adaptive Systems Initiative at Arizona State University and leading communication firm, FKHealth, to create the “portal,” www.iConquerMS.org, for the Network. Please look out for announcements about the launch of iConquerMS or visit the ACP website and sign up for the MS-PPRN newsletter that will keep you informed on our progress.

There are lots of interesting items in this newsletter. Enjoy them all.

Our programs to accelerate research efforts to improve diagnosis, to optimize treatment and to cure MS are expanding rapidly and continue to need substantial financial resources. Thank you so much for your continued support.

With best wishes,

Robert N. McBurney
We first started volunteering at ACP in September of 2013 at the Fenway All Star event. We were both looking for an opportunity to get involved in community service. We discovered this ACP volunteer opportunity online and it sounded like the perfect occasion to start getting involved.

What keeps you involved with ACP? We continue to volunteer for ACP because of the people. Both the employees and participants at the ACP events have been so warm and welcoming to us. Each event we’ve participated in has been more and more rewarding, as we not only take on more responsibilities as volunteers, but also form more connections and memories with the people behind ACP.

Why do you believe in ACP’s mission? ACP’s mission and the people connected to the organization are a reminder of the importance of resilience, community and perseverance in facing adversity. This is a powerful message that definitely resonates with us.

What is your favorite volunteer event? Our favorite event thus far has been the Shoeball, not only because of the fun atmosphere and fabulous footwear, but also because we were able to take on more responsibilities throughout the night.

Do you see staying involved with ACP in the future? Yes, definitely!

What do you wish others knew about ACP? We wish others knew the variety of fun events that ACP hosts and how easy and rewarding it is to get involved and become a volunteer.

What do you do when you aren’t volunteering? We enjoy running, yoga, cooking and spending time with our dog, Maddie, as well as family and friends.

Where did you two meet? We met at a coffee shop in Kevin’s hometown. Emily was a barista and Kevin was her favorite customer!

What might someone be surprised to know about you? We grew up less than a mile apart in bordering towns and attended the same college in Ireland for a study abroad program, but we didn’t meet until years later. We are excited to return to Ireland for our first time together during our upcoming honeymoon! We are getting married on Memorial Day weekend.

Volunteer Spotlight: Kevin Hoffman & Emily O’Connor

On March 15, ACP hosted its 7th Annual Shimmer & Shine Shoeball to raise funds to accelerate research in multiple sclerosis. It was a night of fashion, shoe gazing, dancing, and strutting down the runway to compete for “Best in Shoe!” The judging panel consisted of Boston fashion designers and experts, and local media. They had the challenge of picking best runway strut, sassiest shoe, and best in shoe. Kristie Salerano Kent, a multiple sclerosis patient advocate, singer, songwriter, and author entertained the audience with her story and an original song. Guests heard from five amazing women with MS. They each shared their thoughts on the importance of funding research so one day there will be a cure. After the program part of the evening ended, Jeremy from Boston City DJs took to the runway to start the dance party. No one went home empty handed; everyone received a fabulous swag bag. The night was great fun, filled with fashion, created awareness of MS, and raised the highest amount in support of MS research of any Shoeball to date.

MS Supporters Strut Their Stuff in ACP’s Annual Fashion Fundraiser
CP and its MS Discovery Forum (MSDF) have partnered with statistician Francois Mercier and Khawai, a French firm, to produce a series of unique visualizations of data. The first one is up now at http://www.msdiscovery.org/clinical-trial-viz and its “bubble plots” of data from 106 clinical trials in MS published between 1985 and April.

**Visualizing MS Data**

Sometimes a picture is worth way more than a thousand words—or a thousand spreadsheets. Data visualizations are a way to find relationships in scientific information that may not be obvious by looking at long columns of numbers.
2014, involving a total of 44,606 patients. Blue bubbles mark trials with a positive outcome, brown bubbles mark negative trials, and gray bubbles mark trials that are ongoing or equivalent. The size of the bubble corresponds to the number of patients in the trial. Visitors to the MSDF website can easily sort the data by compound, by trial phase, by dose, by year, by funding, or by population (the type of MS studied).

Sort the data by population, for example, and you’ll immediately be struck by how many trials have focused on relapsing–remitting MS (RRMS), how few have focused on other types, and how few successful trials have been completed in progressive forms of MS.

We plan to add a new MS–related data visualization every month. Among those will be visualizations on the natural course of MS symptoms, on how patients with RRMS differ from those with clinically isolated syndrome, and on how MS researchers are connected with each other. Please watch for these as they appear. Who knows—maybe you’ll be the one to notice a previously undiscovered relationship in the data.

**What The Data Can Tell Us**

As the data visualization shows, there have been far more clinical trials in RRMS than in primary or secondary progressive MS (PPMS or SPMS). This disparity results from the lack of knowledge about the factors that cause and drive progressive MS. While researchers have found that manipulating or suppressing the immune cells that circulate in the bloodstream can reduce disease activity in RRMS, these actions haven’t yet demonstrated much effect in slowing the rate of disability in PPMS or SPMS. Better knowledge about the factors underlying progressive MS is badly needed so that therapies or strategies to prevent progression in MS can be developed.

Also the bubble charts show there have been many MS trials with positive outcomes, and these positive trials have resulted in the FDA approval of 10 MS drugs. However, a positive outcome for a drug in a trial does not guarantee a positive outcome for that drug in an individual with MS. Anyone who starts taking an MS treatment knows that it may or may not reduce their disease activity and it may or may not produce unwanted side effects. There’s always a chance of having to stop that drug and try another. With no knowledge upfront about which drug(s) will work best in which individual, people with MS and their clinicians must resort to trial and error for each treatment decision.

ACP’s New Initiative

Our new project, OPT–UP (Optimizing Treatment–Understanding Progression), is designed to address head–on both of those knowledge gaps. This study will follow 2,500 people over 3 to 5 years and carefully document the factors that correlate with disability progression and treatment outcomes. The data and samples obtained through OPT–UP, when analyzed by researchers worldwide, have the potential to greatly improve the lives of people with MS by helping them to choose treatments that work best for them and to minimize the risk of disability progression through proven therapies or practices.

Working closely with our Repository clinical site investigators and other advisors, we’re nearing the end of the study design process and are now working to arrange the necessary financial support. We look forward to providing further updates as the study grows nearer to being launched.
Diagnosed in 2011, Mason Goché has managed his MS symptoms through diet, exercise, and ample rest. Although his education in renewable energy engineering was sidelined by the onset of MS, after three years of trial and error he is thriving again, even without disease modifying drugs. Mason’s passion led him back to college, at Portland State University, this Spring. Each day Mason rides his road bike seven miles to and from school where he attends science classes in his pursuit of a medical degree.

“Learning about how the immune system responds to different pathogens and antigens is fascinating and inspiring,” Mason says of his favorite class “Communicable and Chronic Diseases” with Dr. Claire Wheeler. That fascination and inspiration is what keeps him going and gives this scholarship winner the power to “Never Give Up.”

The Mary J. Szczepanski “Never Give Up” MS Scholarship Foundation is starting its 15th year of offering 10 scholarship opportunities each year to all U.S. high school seniors and college students. Founder Rick Szczepanski says three components are very important in the Foundation’s mission: Remembering his mom who suffered from MS for 38 years, raising funds for Accelerated Cure Project and its research programs, and assisting students with college tuition.

Young Professionals Accelerating the Cure (YPAC)

This Boston-based group of young professionals serves as an event-planning offshoot of Accelerated Cure Project. They work to educate others about MS and help to raise funds for a cure. Additionally, its members gain hands-on, career-enhancing experience with fundraising, promoting, advertising, coordinating, and facilitating charitable events. The group meets monthly and is actively recruiting new members.

Join ACP on July 6 as We Race Towards a Brighter Future!

The Accelerated Cure Project for MS is proud to be the beneficiary of Rally North America 2014! In 2012, RNA raised over $60,000 for ACP. Rally US 50 - 2014 features 80 teams of two or more people, four racing venues (Summit Point Motorsports Park in WV, Edgewater Sports Park in Cleaves, OH, Gateway Motorsports in Madison, IL and Pueblo Motorsport Park in Pueblo, CO), and 47 stops at historical or scenic locations across the United States along historic US Route 50.

The Rally gets underway on Sunday, July 6 in Martinsburg, WV, and follows a course through Athens, OH; Bedford, IN; Jefferson City, MO; and Dodge City, KS, before ending on Friday, July 11 in Pueblo, CO. The rally participants will travel over 1,600 miles during this cross-country scavenger hunt.

We’d love you to join us at the starting line, at the finish line, or at any stop along the way to support the teams as we travel Miles 4 MS. ACP staff will be driving Team Accelerator. Visit www.rallynorthamerica.com for more details.

Congratulations to 2014 “Never Give Up” MS Scholarship Recipient
Mason Goché

www.acceleratedcure.org
12th Annual Hunt to Cure MS: Born in Boston
Hosted by YPAC
The Bell in Hand Tavern, Boston 10am-4pm

Teams will spend the afternoon scouring Boston and Cambridge for clues to collect points. Each team will consist of a maximum of four people and is responsible for raising a minimum of $500 prior to the event. Teams with the most points will be awarded prizes along with the top fundraisers. Enjoy complimentary food & drinks while celebrating the day at the after party!

Rally North America US 50 - 2014
See page 6 for more details.

The Falmouth Road Race
Falmouth, MA

We still have a few bibs available! Join us for the Falmouth Road Race and raise funds in support of ACP’s mission. This seven-mile race begins in front of the Woods Hole Community Center, near the drawbridge on Water Street. Enjoy the scenic run through the charming town of Falmouth and along Martha’s Vineyard Sound. Registration is $150 per person with a $1,000 fundraising minimum.

All Star Event
Fenway Park, Boston

Our second annual All Star Event is at The EMC Club in Fenway Park! This event is to knock MS Outta the Park, and enjoy an evening of cocktails, delicious hors d’oeuvres, a wonderful silent auction, and much more!!! More information to come!!

Casino Night
W Hotel, Boston

The YPAC is hosting its first casino night at The W Hotel in Boston. Enjoy a night filled with gambling and great friends while helping ACP raise the stakes against MS.

For questions about sponsorship, donations, participation, or general event inquiries, please contact:
Karen Crumback
karen@acceleratedcure.org
Lindsey Miller
lmiller@acceleratedcure.org
www.acceleratedcure.org/events
Welcome Kirsten Bermingham

We are very excited to welcome Kirsten Bermingham to the ACP team. Kirsten joined us this month as a project manager and will be focusing on the MS Patient-Powered Research Network. Kirsten has over ten years of experience working in nonprofit communications, administration, and project management and is thrilled to bring her experience to ACP, as the search for a cure for MS is an issue close to her heart. Kirsten lives in Wayland, MA with her husband and their one-year-old daughter, and when not exploring the greater Boston area with her family she enjoys playing softball, baking, and reading.

Follow ACP Online

Stay connected to the latest news, events, announcements, and research as we work to end Multiple Sclerosis.

Donate today to help ACP in the fight against MS.

Give online at:
http://weblink.donorperfect.com/springnewsletter2014

or call 781-487-0008 for more information.