



October 2016

Dear Friends,

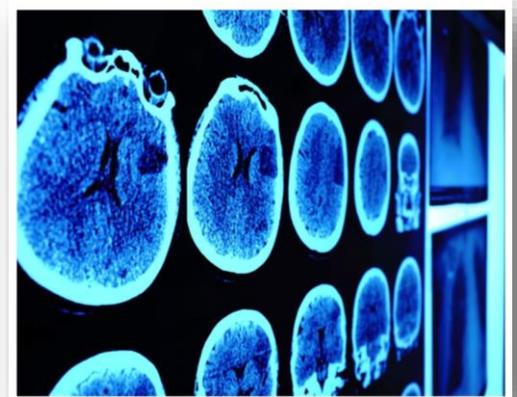
This month we make good on our promise to share with you highlights from the recent international conference on MS research known as ECTRIMS, short for the European Committee for Treatment and Research in MS, the organization that organizes the annual gathering. We describe research that will be of interest to people with primary and secondary MS; additional data from the ORATORIO trial of Ocrelizumab; and, news about the impact of smoking, low levels of vitamin D and obesity on the likelihood that Clinically Isolated Syndrome will convert to MS.

Last month you “met” Linda Kanner, Bruce Sachs and David Blohm, three of the longest serving members of our board of directors. In this issue we introduce you to three additional board members – Jacqui McCoy, Sherry Robinson and Susan Friedman, women whose commitment and hard work inspire us every day to continue working to accelerate research on MS.

And for those of you living in the Boston area, please make room in your calendar to attend the 14th annual *Music to Cure MS* concert on Sunday afternoon, October 30, from 3:00 to 5:00 p.m. at the Park Avenue Congregational Church in Arlington, MA. The concert, which is organized by singer and long-time ACP supporter, Marion Leeds Carroll, features a lineup of experienced artists singing and playing opera, songs and chamber music. More information is available [here](#).

Highlights of the 2016 ECTRIMS Conference in London

Last month we reported that 3 members of the ACP staff attended the world’s largest international conference on MS research, organized by the European Committee for Treatment and Research in MS or ECTRIMS. ACP’s CEO, Robert McBurney, Vice President of Scientific Operations, Hollie Schmidt, and Director of Alliances and Collaborations, David Gwynne, joined other researchers, advocates and health care professionals who gathered in London to hear about the latest updates and research findings on treatment, care and management of MS. The growth of this important meeting is a



barometer of how interest in MS research has mushroomed over the years. In 1996, the first year the conference was held, a mere 800 clinical and research professionals attended. This year, close to 10,000 attendees participated in 65 sessions. A record-breaking 2,036 scientific abstracts were submitted!

Themes of the conference covered the gamut of current MS research interests, including:

- Understanding the mechanisms of MS progression
- Evolving approaches to treatment
- Long-term treatment effects and prognosis
- New insights from registry and cohort studies
- New directions in progressive MS research
- New advances in treatments for progressive MS

During ECTRIMS, our colleagues heard about significant progress being made in these areas and more. Highlights included:

- Research on **Siponimod**, a drug produced by Novartis that is similar to fingolimod. In a large phase III trial called EXPAND, about 1,600 participants received either siponimod or a placebo. Those who received siponimod had a lower risk of progression as assessed by the Expanded Disability Status Scale (EDSS). Novartis's website indicates that the drug company is "evaluating next steps in consultation with health authorities."
- Negative results in progressive MS were found for **fluoxetine (Prozac®)**, a drug that is mainly used to treat depression. It had been thought to prevent brain cells from degenerating. However, in a study designed to test whether it could slow MS progression, fluoxetine failed to produce significant improvement in people with primary or secondary progressive MS (see below for an account of further research being conducted in England to test its impact on secondary progressive MS). Although the trial did reveal a slight trend towards a reduction in disability progression, it was not statistically significant.
- On a brighter note, a very small study (54 participants) of lipoic acid in secondary progressive MS showed a statistically significant effect of this supplement compared with placebo on reducing brain volume loss. A larger study to confirm these results seems warranted.
- By now, most people who care about MS are familiar with **ocrelizumab**, a new MS treatment developed by Genentech that was the highlight of the 2015 ECTRIMS conference in Barcelona due to its positive results in primary progressive MS. In London, additional data was presented by several groups involved in the ORATORIO PPMS trial, showing that the drug consistently produced positive effects on walking and slowed the progression of disability. Other data covered safety and adverse effects, including the occurrence of inflammation and pain at the site of infusion in some people with MS.
- A significant and promising trial called MS-SMART is being conducted at 13 different sites across the United Kingdom, to test 3 drugs and their impact on secondary progressive MS. The 3 are **amiloride**, which is currently licensed to treat heart disease; **riluzole**, currently licensed to treat motor neurone disease; and, **fluoxetine** which, as noted above, is licensed to treat depression. 440 participants with worsening secondary progressive MS have been recruited in 4 groups: (1) placebo, (2) riluzole, (3) fluoxetine, and (4) amiloride. Researchers plan to follow them for 96 weeks to assess the effects of each drug on clinical and MRI outcomes and on disability.

- **Lifestyle factors.** As many of our readers are undoubtedly aware, in some instances MS begins with a first episode of neurologic symptoms that does not fulfill all the criteria for a diagnosis of MS. Called Clinically Isolated Syndrome or CIS, this syndrome sometimes, although not always, develops into MS over time. There is great interest in understanding the factors that cause or trigger conversion from CIS to MS and determining whether they can be controlled. Researchers from the MS Centre of Barcelona (CEMCAT) have followed about 500 people with CIS for an average of 8 years, trying to determine whether any relationships exist between low levels of Vitamin D and smoking at the time of diagnosis, and later conversion to MS. Using a biomarker of smoking (cotinine) in people with CIS they found no significant increase in conversion to MS in people who were smokers or who possessed low levels of vitamin D. However, both factors were significantly associated with the development of higher disability in the study's participants. They concluded that both risk factors, if modified, could slow the progression of disability in people with CIS.

Another study, conducted by the Danish MS Center, showed that smoking has a significant effect on the way that people with relapsing remitting MS who are treated with injectable interferons respond to that treatment. They found that people with MS who smoked more were less likely to respond to interferon treatment.

Researchers from the University of California, Berkeley and the University of California San Francisco who followed about 2,000 Americans and Swedes with MS (and healthy controls) found a causal connection between an abnormal increase in weight and the risk of MS. They suggested that the cause might be the effect of obesity on the immune system.

These and other important developments make clear that interest in MS research is growing around the world and the work being done is dynamic and holds enormous promise. As a leading organization providing essential resources to make MS research worldwide go faster, be more effective and focus on the needs of people with MS, ACP plays a unique and important role. Our Repository (which you yourself may have contributed to) recently passed the milestone of approving 100 research studies worldwide, enabling research studies with biosample and data resources that would otherwise have been delayed or too cost-prohibitive to conduct. Far from being a passive resource for researchers to "come and get," we are transforming the Repository into a pro-active enterprise that:

- a) expands and enhances itself in ways that generate and refresh its resource offerings consistent with the needs of researchers and the major directions of MS research;
- b) understands itself through preliminary data analyses to determine what assets hold the greatest value for particular research studies (the "jewels"), so that researchers can be alerted; and,
- c) actively markets itself to researchers worldwide to ensure that studies are undertaken to capitalize on the "jewels" and generate research findings that will benefit people living with MS.

Introductions to More ACP Board Members

Last month, we wrote about three of the longest serving members of ACP's Board of Directors, promising to "introduce" you to others in the coming months. In this issue, we present Jacqui McCoy, Susan Friedman and Sherry Robinson, three resourceful and determined women on our board, whose commitment to ACP inspires us every day. Not one is a passive presence; all three regularly roll up their sleeves and do the hard work of ensuring that ACP utilizes its resources to make the maximum impact on accelerating research on MS.

Jacqui McCoy

After being diagnosed with MS in September of 2000, Jacqui and her husband Mark made an effort to learn all they could about this disease. They found many organizations that did a great job of helping individuals and their families learn to live with MS. However, living with the disease was not enough; they hoped there would be a cure.

Jacqui and Mark were excited when they learned about Accelerated Cure Project (at the time called Boston Cure Project) through a newspaper article that described the organization's objective of finding a cure! A meeting with ACP's leaders expanded Jacqui's understanding of its strategy to improve on the traditional research efforts of the medical community. The plan made more sense than anything else she had heard about. Eager to help, she joined the board in 2003 and served until 2006. After a hiatus of 9 years, Jacqui rejoined the ACP Board in 2015.

Jacqui is co-owner of Paul | McCoy Family Office Services LLP – a multi-family office. Their unique business model combines more than forty- five years of experience as CPA's with the expertise and willingness to manage the complex details and issues of wealthy families. Jacqui's financial skills serve ACP well.

Jacqui was raised in Washington State and earned her undergraduate degree at Babson College. When not working, she can be found out on the golf course, traveling, watching sports or enjoying fly fishing. She lives with her husband in Boston.



Susan Friedman

Susan Friedman is a strategy consultant with her own practice, serving both for-profit and not-for-profit organizations. She began her career with the Boston Consulting Group, later working with Telesis, Inc. and Alliance Consulting Group. In her own practice, established in 1992, Susan helps clients to identify and assess growth opportunities, evaluate competitive dynamics, understand the economic model underlying their organization's financial performance, and assess the internal alignment of the organization's operations and the "match" between the needs of a target market and the organization's capabilities.



Susan was educated at Brown University (BA), the London School of Economics and Harvard Business School (MBA), and was introduced to Accelerated Cure Project by fellow HBS alumna, Linda Kanner. For several years she watched helplessly as one of her sisters suffered (and ultimately passed away) from MS. Out of a personal desire to do something positive for MS and excited by ACP's goal of accelerating research towards a cure, she volunteered to help ACP revitalize its strategy. The 6-month assignment provided ample exposure to ACP's work, staff and to its board. In 2014 she became a member.

Susan is a trustee and former Chair of Boston Ballet, on the Board of Advisors for Jewish Family and Children's Services, and has previously served as Co-Chair of the WGBH Community Advisory Board, trustee of Lesley University and of the Boston Philharmonic Orchestra.

Sherry Robinson

Sherry Robinson has worked in both for-profit and non-profit environments and she brings lessons from each to her board service for ACP. In the corporate sector, her experience is primarily in public accounting. In the non-profit world, Sherry has worked to address the needs of children in protective custody, the hungry and the mentally disabled. She became keenly focused on finding better treatments and a cure for MS in 2010 when her then 28-year old daughter was diagnosed with the disease. Sherry's path to Accelerated Cure Project followed her own journey of self-education about the science and medicine of MS, as she sought to understand the disease, existing treatments, research towards a cure and, ultimately, the prognosis for her daughter's life.

A self-described non-scientist, Sherry's hunger for information obliterated all fear of pursuing access to the country's leading neurologists and neuroscientists to serve as her teachers. The result is that she possesses a deep and detailed understanding of this complex disease, while continuing to stay abreast of the latest work on treatments and cures by reading and by attending the annual conference of the European Committee For Treatment and Research In MS (ECTRIMS). It's no surprise, then, that Sherry found Accelerated Cure Project in 2014. She joined ACP's board in 2015.

A graduate of the Wharton School (BS) and a CPA, Sherry worked for Ernst & Young; KPMG, and GECC for a decade. After she left accounting and while residing in Houston, TX, Sherry applied her financial management skills in the non-profit sector. She was a member of the founding board of a public/private partnership called BEAR...Be A Resource for CPS Kids, serving the needs of children under the care of Child Protective Services. Over the years it grew, and with a still healthy budget today it continues to mobilize hundreds of volunteers and to serve 17,000 children. Following that, Sherry served as Executive Director of End Hunger Network, a food rescue organization, launching a fresh-meat initiative that provided thousands of meals to Houston's hungry. It has since merged with the local food bank and continues to feed hungry people across Houston. Since moving to Boston's Back Bay with her husband, George Fink, in 2005, Sherry has joined Old South Church where she is a member of the Council.



October 30th – Save the Date for Music!

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