

3RD ANNUAL BOSTON CURE PARTY: EXCITEMENT AND ENERGY!

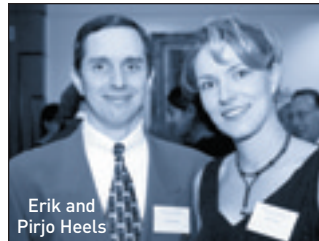
The third annual Boston Cure Party was held at the MIT Faculty Club on Saturday, November 22nd, from 6:30 p.m. to 10:00 p.m. Two hundred and six guests in cocktail attire mingled, munched, and got all fired up about the astounding number of accomplishments Boston Cure Project achieved in 2003 and its ambitious plans for 2004.

Dr. Michael Racke delivered a special pre-party lecture about immunology of Multiple Sclerosis. Michael K. Racke, M.D. is Vice Chairman for Neurology Research and Director of Neuroimmunology Research at the University of Texas Southwestern Medical Center at Dallas and is also on the Boston Cure Project's Scientific Advisory Board.



Ann Nora Ehret, Marianne McGaffigan,
Fiona Reardon, Jennie Kinney, Jill McGaffigan

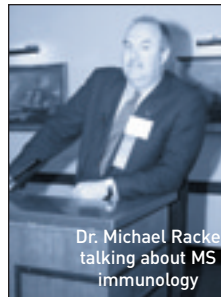
Later in the evening, Art Mellor ushered everyone into the main room for the evening's speakers and presentations. Our guest of honor, Gerald D. Fischbach, M.D., delivered a presentation on the controversial issue of stem cell research, exploring the ethical dilemmas of the research and its legal complexities. Dr. Fischbach is Executive Vice President for Health and Biomedical Sciences; Dean of the Faculties of Health Sciences and Dean of the Faculty of Medicine at the College of Physicians and Surgeons of Columbia University. He served as Director of the National Institute of Neurological Disorders and Stroke, National Institutes of Health from 1998 - 2001.



Erik and
Pirjo Heels



Dr. Maggie Harling
with her silent
auction winnings.



Dr. Michael Racke
talking about MS
immunology

Next, Dr. Tim Vartanian discussed Boston Cure Project's imminent Multi-Disciplinary Blood, Tissue and Data Bank, and the impact Boston Cure Project's work will have on the medical and scientific fields. President Art Mellor then delivered an update on the impressive progress made by Boston Cure Project in the last year.

At the end of the presentation, Art took the opportunity to express his thanks to the many volunteers who helped out in the past year and without whom the Boston Cure Party would not have been possible.

During the evening there was a bounteous silent auction for guests to peruse; from sports tickets to jewelry and handbags, to champagne and caviar.

Guests lingered after the presentations for dessert, coffee, more conversation, and to take in the lovely view of the Charles River and the Boston skyline. By the end of the evening, the Boston Cure Party brought in over \$27,000 in sponsorships, individual contributions, and silent auction purchases.

Our Generous Sponsors for the Boston Cure Party were:

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LETTER FROM THE PRESIDENT

The last quarter has been fruitful. Our third annual Boston Cure Party went off extremely well, featuring guest speakers Dr. Gerald Fischbach, Dean of the Columbia Medical School and former Director of the National Institute of Neurological Disorders and Stroke and Dr. Michael Racke, Vice Chairman for Neurology Research and Director of Neuroimmunology Research at the University of Texas Southwestern Medical Center at Dallas. Pictures are available in the Events section of our web site.




In December, we received provisional approval for our tissue bank effort at the Beth Israel Deaconess Medical Center in Boston. We made the few modifications they requested and the modified protocol will be reviewed on March 1st.

We've completed the first round of Phase 2 documents for our Genetics track on the Cure Map. These documents comprise a complete review of research done into the causes of MS as they relate to genetics. These documents are available for download in the Cure Map section of our web site.

The 3rd Annual Hunt to Cure MS Scavenger Hunt will be held on Saturday, May 22nd starting at the Skellig in Waltham. Details and registration information at www.bostoncure.org/hunt. Sign up now!

Regards,



Art Mellor
President & CEO
Boston Cure Project, Inc.

CONTRIBUTE YOUR VEHICLE



The Boston Cure Project can accept donations of vehicles through America's Car Donation Charities Center. To donate a vehicle, contact us and we will email, fax, or mail you a form to fill out (or you can download a PDF version from our website: <http://www.bostoncure.org/downloads/vehicle.pdf>). Return the filled out form to us and we'll submit it to America's Car Donation Charities Center. They will take care of all the details of arranging pickup, disposal or sale of the car, and delivery of your contribution to us. For their services, they keep 30% of the funds. You can get more details at <http://www.bostoncure.org/about/vehicle.php>.

BOSTON CURE PROJECT: IN THE NEWS

Boston Cure Project received quite a bit of press recently due to the number of events we hosted this past October and November.

The third annual Boston Cure Party received calendar plugs from nearly all of the major Boston papers and on-line news sources, and from **Bio-IT World** as well as the **Boston Business Journal**. Sing to Cure MS, our Halloween Concert in October received coverage from the **Arlington Advocate**.

Art Mellor was also featured in a five-page spread of October's **Fortune Small Business** magazine, marking Boston Cure Project's first national press exposure.

Thanks to **Krista Milne of Mojo Marketing** for her persistent public relations efforts and support.

FITSENSE – SENSE OF PURPOSE



Father Bernard Marton crossing the finish line of the Chicago Marathon on October 12, 2003, his efforts raising \$9K for BCP.



Michael Frech of Wayne, NJ (center) with wife Sue Frech (in BCP T-shirt) surrounded by friends following his completion of the Philadelphia Marathon on November 23, 2003 through which he raised over \$8K for BCP.

Tal Viskin, senior at George Washington University, ran the Baltimore Marathon on October 18, 2003 to raise money for BCP in honor of Anna Peabody.



SING TO CURE MS

Sing to Cure MS, the Boston Cure Project's Halloween concert, took place on Sunday, October 26 at the Pleasant Street Congregational Church in Arlington. The event, which generated more than \$5,900 in total proceeds, was a great success featuring amateur and professional singers from the Boston community as well as the Brookside Elementary Chorale from Dracut.

The two-hour program featured spooky songs and arias to suit a Halloween theme. It was followed by a raffle during which a variety of prizes donated by Bertucci's, Henry Bear's Park, and the New England Gilbert and Sullivan Society were given away to winning recipients.

The entire concert was organized by volunteer, Marion Leeds Carroll, an accomplished opera singer and director from Arlington for whom Boston Cure Project's mission truly strikes a chord. Marion herself has MS and wanted to put the talents of her professional community to work in raising money for our organization.

A great time was had by all and Marion is looking forward to doing it again next year. Thank you to her, to all the local businesses who supported the event, to corporate sponsors, Teva Neuroscience and American Express Financial Advisors, as well as all of the generous attendees, volunteers, musicians, and singers who made the event possible.

TEE OFF TO CURE MS

On October 8, Boston Cure Project held its first-ever golf tournament. Organized by Hank Tuohy of Tuohy Sports and Entertainment, the event was held at the prestigious Pine Hills Golf Club in Plymouth.

The event featured a variety of great prizes, drawings and auction items, as well as many celebrity players. Wilbur Wood, Hall of Fame Baseballer who invented the knuckleball and played for the Chicago White Sox, Peter Vass, Coach of the international NFL team, the Berlin Thunder, boxer Kip Diggs, Jim Delgaizo, former Miami Dolphin, and Tom Stephens, former Boston Patriots all joined us for a great day of golf.

Congratulations to David Lee, John Swift, Andrew Wilsak, and Bobby Coppins for taking first place in the tournament. Special thanks to Atlas Venture and Robertson's GMC, our leading sponsors, and to all of the other individuals and businesses donating gifts and participating in the event.

RECOMMENDATIONS

FOR THE MS RESEARCH AND FUNDING COMMUNITIES

By Art Mellor

We're often in the position of telling people what the Boston Cure Project thinks should be done in the areas of MS research and funding. We thought we'd share our views by presenting them in this article.

There are three broad areas of research focus that we feel are under served given their importance to stopping MS in people who have it. The first is determining the causes of MS, which is our primary focus. We believe the fastest route to a cure will come from knowing the causes of MS. Presumably, if the cause is understood, progression of the disease can be halted by interfering with or eliminating the cause, and future cases may be prevented altogether.

The second area is neuroprotection and repair. This is about slowing progression and restoring function that has already been lost. This is a critical area for many neurological diseases and is being looked at by more and more researchers. But without knowing what's causing the damage, we can't be sure that any restorative procedures won't be undermined by the active disease.

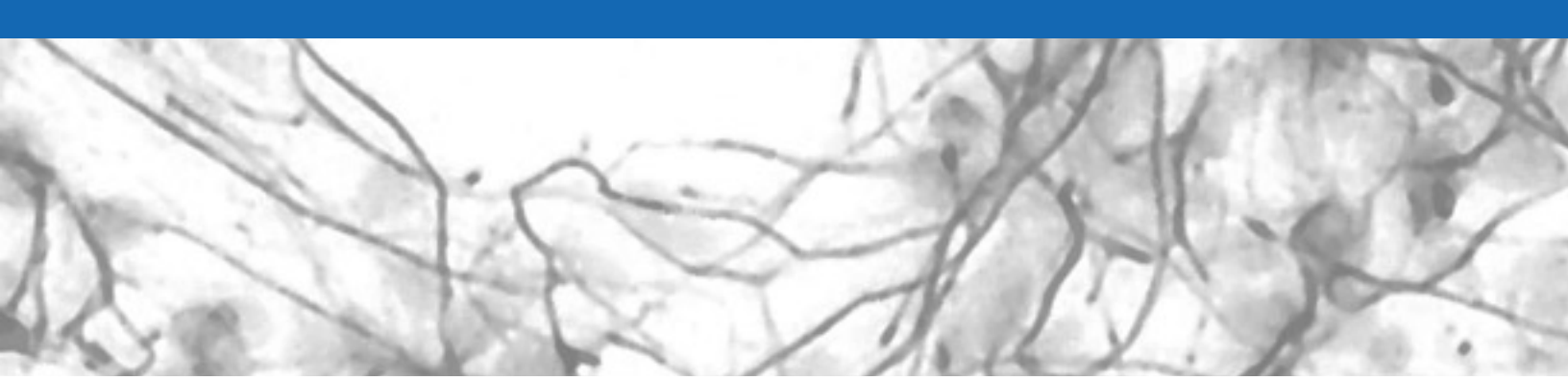
The third area is determining much more about the human pathophysiology of the disease. Understanding what is happening in MS in humans, rather than animal models, will be key in developing any significant treatments.

What specific things can be done to help address these three areas? Here is a brief list of some things we think would improve the output of MS research:

- **Study humans more, and animals less.** Currently a very large percentage of the dollars spent on MS research goes to studies using animal models of MS (almost 25% of research dollars spent). Mice do not get MS. Studies on mouse models of MS do not tell us as much as we would like about MS in humans. That having been said, it can be difficult to study human subjects. For instance, humans don't like to have their brains dissected and analyzed (at least while they are alive!). This implies that we need to invest more in collecting post-mortem brain tissue from people with MS or develop better non-invasive methods of analysis.
- **Improve imaging techniques.** One way to study humans is to improve our imaging technologies so that we can non-intrusively look inside a living human's brain. We can currently do this with MRI, but at a fairly low resolution. We need to be able to directly image myelin and axonal damage if we want to understand how these effects occur. Based on the potential of this technology

to answer important questions about MS, we feel this is an area that deserves more investment.

- **Find bio-markers for disease activity and treatment response.** Another way to study humans using minimally invasive techniques is to analyze samples that are easier to obtain than brain tissue. Finding markers in the blood of people with MS that can measure disease progression and activity can be used to more easily diagnose and to measure response to treatments.
- **Do larger studies.** Most MS research is conducted on small groups of people, usually tens of people, sometimes hundreds, and very rarely thousands. MS is widely considered to be a family of diseases with a common end point, as opposed to a single disorder. This means that a study of 50 people with "MS" might have a very small number of people each with a different type of MS – making statistically valid conclusions difficult to draw. We need to be looking at thousands of people at a time. This is one of the aims of our blood and tissue bank, to collect a very large number of samples so that very large studies can be done.
- **Look across disciplines.** Evidence indicates that MS is probably not caused by a single underlying factor such as a particular gene or pathogen, a single nutritional deficiency or environmental toxin, or a specific trauma. It appears to be a combination of several of these together, for example, a genetic predisposition and an environmental trigger. Most likely MS is a different set of combinations in different groups of people. This means that studies conducted in just one area are unlikely to reveal the causes. It is necessary to have researchers in different disciplines studying the exact same subjects so that correlation's from research in one discipline to the other will be meaningful. This is another aim of our blood and tissue bank, to collect samples and data that can be useful to researchers in different disciplines which will allow us to combine the data from multiple studies.
- **Try more combination therapies.** Because MS is likely more than one disease, it only makes sense that a single drug is unlikely to treat it very well. It will probably be necessary to treat it with a combination or "cocktail" of drugs. Also, the "one size fits all" model of treatments should be revisited. To assume that a ninety-eight pound woman should be taking the same dose of a drug with serious side effects as a four-hundred pound man does not make sense.



- **Fund larger efforts.** The funding for most MS academic research is in the \$50K to \$300K range. This puts a serious limit on the size and types of studies that can be done. There are few significant projects in any human endeavor that can be done in that price range. Some projects necessary to fully understanding MS will undoubtedly take millions of dollars and cannot be realized without a focused, committed effort. We need to think about what could be done if we applied much more funding to fewer projects.
- **Have a plan.** In order to appropriately use a large budget, you should have a plan of what you hope to accomplish with it. Much MS research funding uses a “shotgun” strategy – funding many different ideas to see if any of them hits the target because we don’t know what we need to do. Sometimes you get lucky, but we’d like to see a more directed approach taken. It should be clear how any given research fits into an overall picture filling in what we don’t know in a manner that will lead to a cure. This is the strategy behind our Cure Map program which is detailing what we know, what we need to know, and how to go about knowing it regarding determining the causes of MS.
- **Develop computer models.** MS is a very complex disease that involves many aspects of human biology. There is too much information to hold in one person’s head. It is important that we start to build computer models of our understanding of the disease to record our knowledge and test our assumptions about what is happening.
- **Changes to the FDA approval process.** The current system used to approve medications in the US is very slow. Even if we had a promising new candidate drug today, it would be years before most of us would get access to it. For progressive diseases like MS, this is not a good solution. One of our Scientific Advisory Board members, Peter Lansbury, has proposed some interesting changes that could help. You can read about them here: http://hcnr.med.harvard.edu/downloads/Wash_Post_op_ed_Nov_16_03.htm
- **Measure success by milestones, not dollars.** We are often quoted large numbers as a measure of progress in MS research, such as a certain number of research programs funded or a dollar amount spent. The only measures that

We need to think about what could be done if we applied much more funding to fewer projects.

matter are the number of people with MS whose lives have been improved or the specific steps taken toward that goal. This ties in with the idea of having a plan. We need to ask how each funded project specifically takes us closer to a cure. Research aims should be able to be stated in clear and uncertain terms that make sense in the context of the larger goal of curing MS. Also, we should not consider advances from other fields that help MS as validation of prior unrelated work done in MS.

In closing, here is a list of questions that we feel are fundamental to understanding in MS. It seems amazing to us that after over a century of scientific research into MS, these very basic questions are still unanswered. Perhaps a few changes in how we study the disease will lead to these answers – and a much better outlook for those of us living with MS.

If MS is caused by genetic and/or environmental factors, how could two genetically identical twins who grew up in the same house together, attended the same schools, were exposed to the same germs, etc. be discordant?

What causes an exacerbation of symptoms?

What makes it go into remission?

Why do the types of symptoms experienced vary from person to person, or even from relapse to relapse in the same person?

What causes a lesion to start forming in a certain spot? What makes it stop growing?

Why doesn't MS affect the peripheral nervous system?

Why do some people start off with the relapsing-remitting form of MS, while others are progressive from the very beginning?

What makes someone go from relapsing-remitting to secondary progressive?

What destroys the myelin in MS? How do axons get damaged?

Why do twice as many women as men get MS?

Why does MS typically strike people as young adults? Why not as children or as middle-aged or elderly adults?

CURE MAP UPDATE

As reported in the Letter from the President, the institutional review board at the Beth Israel Deaconess Medical Center has approved the study protocol for the pilot phase of our multidisciplinary blood, tissue and data bank. Soon we will start collecting, processing, and storing blood samples from MS patients and family controls, and distributing them to scientists searching for the causes of MS. Because the samples we collect will be useful for many types of experiments, and because they will come with a wealth of medical history and other data, we hope that over time they will let us iden-

tify combinations of factors — genes, infections, toxic agents, etc. — that increase the risk of MS.

Our Phase 2 Genetics documents are now available on our web site along with an updated version of our MS genetics spreadsheet. Our next major focus is the Phase 2 of the Infectious Agents track, which we just started tackling. We've also been able to make headway on Phase 1 of the Nutrition track through the efforts of our January MIT intern, Anupama Bhimavarapu.

CONGRATULATIONS CORNER

We all send our best wishes to Boston Cure Project volunteer Dr. Maggie Harling and her new husband, Brant Viner. The happy couple married on September 10th, 2003 at Worcester City Hall. Maggie told us that the "raccoon" look she's wearing in this picture is for real—she fell and broke her nose just two days before the wedding, and two black eyes were the result. She probably swooned with happiness, don't you think?



VOLUNTEERS

Our volunteers are a precious resource! These generous folks have been giving their time to Boston Cure Project in late Fall/early Winter.

VOLUNTEER STAFF

Debbie Mellor - *Contributor Acquisition*
Susan Mellor - *Administrative Assistant*
Stephanie Sisto - *Intern*
Anupama Bhimavarapu - *Intern*

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David Flannery
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Kelly McGowan
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Dave Kaffine

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Charlie Namias
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David Wiesen
Graham Wright

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John Capello
Emeka Iffih
Jeff Kim
Jan Klein

PHARMA DATABASE

Belinda Vandervoort

TEE-OFF TO CURE MS

Jim Delgaizo
Kip Diggs
Krista Milne
Ed Raws
Dave Ray
Tom Stephens
Bobby Trieger
Peter Vaas
Wilbur Wood

OTHER

Theresa Hahn (*web site*)
Sujit Purkayastha (*cure map*)
Justin Polanik (*clerical assistance*)
Michael Polanik (*transportation*)
Michael Silton (*CME project*)
Stephanie Sisto (*MS research spending analysis*)
Frank Siteman (*portrait*)
Stan Vernon (*grant writing*)

Pam Wolf (*recruiting*)
Kevin Wood (*Entelos project*)

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If for any reason you've been left off this list in error, please let us know so we can include you in our next issue!

T-SHIRT PICTURES

WANT A BOSTON CURE PROJECT T-SHIRT?

Visiting an exotic (or not so exotic) locale? If you offer to take a picture at your destination with a Boston Cure Project T-shirt on, we'll send you one for free!



Andy Monk from England who, on April 18, 2004, will start a 500-mile journey across England, Belgium, Holland, and Germany (Bury to Bremen) following the route his father took with D Company, 7th Battalion, The Cameronians (Scottish Rifles) during WWII - all to raise money for MS research.



Development Manager, Melissa O'Shea, in Ireland, outside of Galway at the cliffs of Moher.

Sharon and Sean Shen at Interlaken, Switzerland



Brian and Tony Mellor on Lake Michigan pier in Port Washington, Wisconsin. Tony was visiting from England.

VOLUNTEER PROFILE: DEBBIE MELLOR

Sales Professional, Devoted Wife, Star Volunteer

by Melissa O'Shea

"When Art was first diagnosed, to say that it was a complete shock would be an understatement," says Debbie Mellor. That was in 2000. Debbie and Art Mellor were on top of the world, thinking about getting married, very much in love. Things were going great career-wise for both of them. The news of Art's MS diagnosis was an unexpected bombshell.

Thankfully, Debbie and Art didn't let it stand in their way. They were married in August of 2001, the same year Art co-founded the Boston Cure Project.

Maybe you've seen Debbie at a Boston Cure Project event or noticed her name on the list of volunteer acknowledgements in every newsletter. Debbie not only works full time as an Account Executive at OPNET Technologies where she sells complex network modeling solutions to the ranks of America's Fortune 500, but she also spends an incredible amount of time working for the Boston Cure Project as a volunteer.

Logging countless hours in volunteer service, she's taken on tasks that range from stuffing envelopes to driving 300-person events such as the Scavenger Hunt, which netted over \$35,000. Most recently, Debbie organized the silent auction for the third annual Boston Cure Party, an effort she pulled together in three months that raised \$4,000.

Though the loving wife and devoted volunteer description conjure up images of June Cleaver and Martha Stewart, Debbie is anything but square or stuffy. Behind the high

tech title, Colby College degree, years of classical piano lessons, and an incredible ability to master foreign languages, is a big hearted, fun-loving individual with one of the best senses of humor known to man.

As Debbie proudly dons her purple leopard print manicure (a recent but avid fan of nail art) and her matching ostrich feathered handbag, I wonder how someone so nonchalant and light-hearted can pull off such an incredible resume of achievements and accomplishments, not the least of which is being adored by all those who know her best.

At least one of the key ingredients is keeping busy. Debbie tells me that every once in while she and Art declare that they are taking a chunk of time off to do nothing at all. Just relax. And they end up hating it. According to Debbie, working for the Boston Cure Project provides a sense of empowerment.

But it's Debbie's dedication that empowers others, including those of us here at the Boston Cure Project - that and her positive outlook on life.

"We have no idea if, when or how the MS will strike. At any moment, my husband could become disabled. That might be next week, it might be next year, it might be never. Regardless, we're not going to spend the healthy times in tears or in a state of misery. I won't let that happen. We live and enjoy each moment as it happens. It's just a good mantra to live your life by, MS or no MS."



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ABOUT MULTIPLE SCLEROSIS

Multiple Sclerosis is a chronic demyelinating disorder of the central nervous system that often results in severe disability including the inability to walk, blindness, cognitive dysfunction, extreme fatigue and other serious effects. MS affects over 400,000 people in the US and 2 million individuals worldwide. The disorder occurs twice as often in women as in men. The cause is not known and there is no known cure.

CONTRIBUTE TO BOSTON CURE PROJECT:

By Check: make checks payable to Boston Cure Project, Inc., and mail to:

Boston Cure Project, 13 Belton St. Arlington, MA 02474

By Credit Card: on www.bostoncure.org, click on the "Contribute" box at the top of the page and follow instructions under the heading "Donations by Credit Card."

Volunteer Today: See www.bostoncure.org for volunteer opportunities, or call at 781-788-0880, or email at newsletter@bostoncure.org.

Want a Boston Cure Project T-Shirt? For any donation of \$25 or more, we will send you a t-shirt upon request. If you offer to send us a picture of yourself in one of our t-shirts at some unusual locale, we'll send you one for free! **Please remember to indicate t-shirt size when making your request.**

Subscribe Now to Our Newsletter: call 781-788-0880 or email us at newsletter@bostoncure.org. You may also unsubscribe using this contact information.

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bcp-announce Occasional announcements regarding events, important news, new mailing lists, etc.

bcp-status Monthly, more detailed updates of what we have been doing on a regular basis. Includes more information on our week-to-week operations.

bcp-volunteer Sign up for this list if you would like to volunteer. We'll contact you as volunteering opportunities arise.

MS NEWS WEB SITE: PRODUCED BY BOSTON CURE PROJECT

MS News is the first interactive online source of MS-related news and research updates. MSNews provides a place for the MS community – individuals with Multiple Sclerosis, family members, clinicians, scientists and others to read and submit the latest news and research updates, participate in discussions on MS topics, and stay up-to-date on the issues that affect them most. Available free of charge by visiting msnews.bostoncure.org.

Have you moved? Changed your email address?

Let us know! Send changes in contact information to newsletter@bostoncure.org or give us a call at 781-788-0880!

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