

## 3<sup>RD</sup> ANNUAL SCAVENGER HUNT: A FUN-FILLED SUCCESS

**T**he Third Annual Hunt to Cure MS kicked off with a bang on May 22nd at The Skellig in Waltham. Nineteen teams raised over \$30,000 in sponsorships and corporate donations.

Despite the cold weather, the mood inside The Skellig was frenzied and hot as volunteer staff arrived early to set up and decorate the backroom, arrange the huge breakfast spread donated by Dunkin' Donuts and Russo's market, and register the teams as they arrived.



The teams tally their points for the judges.

Master of Ceremonies Bryan Gildenberg fired up the crowd and thanked The Skellig's co-owner Tommy McCarthy for donating his bar and food for the Hunt. Mayor Jeannette A. McCarthy (no relation to Tommy) of Waltham thanked everyone for coming out and participating in such a worthy event. Then she sent each team captain off with the official list and rules – and the hunt was underway!

After the day of work, the excited and hungry teams arrived back before the 5:00 deadline—some opting to go straight for the food while others headed to the judging tables for scoring. Some were said to have negotiated an exchange of belly button photos out in the parking lot.

Eleven teams of judges verified items such as meat-flavored potato chips, tinfoil animal sculptures, a picture of rival drugstore employees shaking hands, and a picture of team members wearing towels and standing around a watercooler.

The Honorable Michael J. Pomarole and his sidekick Julie Baker presided over any challenged rulings.

Competition was fierce this year. Girls on the Run placed first by a large margin after their year's worth of training since the last hunt. Hunters and Gatherers vaulted from third place to a tie for second based on the strength of Peter Schmidt's winning performances in both the Howard Dean impersonation and squidgy a wink contests. However, Five Hip Chicks claimed second place when they won the "guess Art's weight" tiebreaker question.

Amid the excitement, the Howard Dean impersonations rocked The Skellig. Eleven teams competed to have their designated member act out an interpretation of Howard Dean rallying his team. The contest was judged with the "applause-o-meter" and the final contestant, Peter Schmidt, won in a rousing rendition of the no microphone, rolled up sleeves, overzealous team leader.

The 2004 Hunt to Cure MS was a rousing success thanks to the many volunteers who worked hard planning, publicizing and running the event. Joanne Minassian, Debbie Mellor, Sue Mellor, Melissa O'Shea, Lisa Sargeant, Sabrina Sequeira, Kellie Trainor and Belinda Vandervoort planned the event. Many more volunteers ran errands, made deliveries, secured donations, designed materials, judged teams and processed data entry or accounting. We couldn't have done it without them – thank you everyone.



Bad News Bears members Dan, Anthony and Jay

Thanks to our generous sponsors: CVS, West Suburban Imaging, Skelmir, The Skellig, Sun Life Financial, Scott Goffstein and Associates, Avery Dennison, and Kevin Song Realty.

View the complete list and the winners on the Boston Cure Project website at:

[www.bostoncure.org/events/eventpages/20040522\\_hunt04.php](http://www.bostoncure.org/events/eventpages/20040522_hunt04.php)

You can also view the amazing videos and sign-up information on the 2005 event here.

## LETTER FROM THE PRESIDENT

Usually we send out our newsletter quarterly, but this issue is our combined Spring/Summer issue, covering the last 6 months. Due to bringing on our new Operations Manager (and newsletter editor), Julie Morgenlender, and moving into new space, we fell a little behind in our printed updates. We promise to get back on the quarterly schedule with our next issue!



As usual, we have more to report than we can fit in a small document like this. In this issue we cover more of the logistics surrounding the upcoming Tissue Bank (now in budget and contract negotiations at two hospitals), the results of our 3rd Annual Hunt to Cure MS Scavenger Hunt, our new Expansion Team Program, and a variety of other accomplishments and upcoming events.

If you'd like to get monthly updates via email on what we are doing, you can receive them by clicking on the "Sign Up" button at the top of every page of our web site at [www.bostoncure.org](http://www.bostoncure.org).

Regards,



Art Mellor  
President & CEO  
**Boston Cure Project, Inc.**

## BOSTON CURE PROJECT HAPPENINGS

### RECENT NEWS

On Saturday, May 2 Boston Cure Project moved to our new location, at 300 Fifth Avenue, Waltham, MA 02451.

Boston Cure Project is happy to welcome Koby Mok to our Pharmaceutical Advisory Board and Ruth Ann Marrie, Larry Steinman, Peter Calabresi and Amit Bar-Or to our Scientific Advisory Board.

Bios are available at <http://www.bostoncure.org/about/people.php>

Boston Cure Project welcomes two interns this summer, Irene Rahman and Brian Keegan, both students at MIT. Irene and Brian are working on Phase 1 of the Cure Map for toxic agents and nutrition, respectively.

Our booklet for the newly diagnosed, *So, You have Multiple Sclerosis... What's Next?*, is here! It is available here: <http://www.bostoncure.org/msresources/library.php>

### UPCOMING EVENTS

Contact BCP for more information on any of these events.

We're already preparing for our next MS Social. Keep an eye out for the date, to come. If you'd like to organize a social in your area, please contact us for information on how to do it at 781-487-0008.

After last year's success, our Cut-a-thon is returning this fall. Check our website for details, to come.

Our October Concert is only a couple months away. Come join us for an evening of fabulous music on October 24, 2004, 7-9pm at the Pickman Recital Hall at the Longy School of Music in Harvard Square, Cambridge.

Watch for information about our 4<sup>th</sup> Annual Boston Cure Party, which will be held at MIT's faculty lounge on November 20, 2004.

# START YOUR OWN EXPANSION TEAM

If you or someone you love has MS and you're excited by the idea of rallying others in support of a cure, Boston Cure Project invites you to start your own "Expansion Team." The Expansion Team program allows you to create a personal fund – a fund in the name of a person, group or place that is special to you – and through this personal fund, you, your friends, family, and community raise money using our special turn-key fundraising kits and support. Your proceeds benefit the Boston Cure Project, thereby furthering our work in determining the causes of MS – all in the name of your personal fund.

The Anna Peabody Fund is our first Expansion Team, created in 2002 in honor of Anna Peabody, who was diagnosed with MS at age 15. Since then, Anna, her friends, and her family have raised more than \$148,000 through fun events, initiatives, and letter campaigns.

You can make a difference too! Here's what's involved:

- Boston Cure Project will set up a fund in the name you choose, taking care of the legal and financial aspects.
- Our advisors will provide you with a kit of information that will allow you to quickly and easily conduct letter writing campaigns and fundraising events of all kinds. They will work with you to determine the specific initiatives you would like to conduct in a given year or timeframe.
- You will receive support, guidance, advice, and organizational assistance so that your events are successful and rewarding.
- You will be invited to customize a personal web site for your fund through which you can raise money on-line. You only need to know how to use a browser to do this.

Starting your own Expansion Team is a great – and easy! – way to rally those closest to you in support of the efforts of Boston Cure Project. To find out more about starting your own Expansion Team, contact us at 781/487-0008 or email [melissa@bostoncure.org](mailto:melissa@bostoncure.org) for details.

## EMPLOYEE PROFILE: JULIE MORGENLENDER

### NAME/NICKNAME:

Julie Morgenlender

### OCCUPATION:

Operations Manager, Boston Cure Project

### REASON FOR JOINING BOSTON CURE PROJECT:

I wanted to do something useful, helpful. I particularly wanted to help find cures for chronic diseases. When I read about Boston Cure Project's cure map and tissue bank I thought, "This makes so much sense, why hasn't it been done before?" I knew I wanted to be a part of making it come to life.

### LAST JOB/OCCUPATION:

Before I came to Boston Cure Project, I was a graduate student in Linguistics at the University of California, Los Angeles. I was also a teaching assistant in the linguistics department for an Introduction to the Study of Language course. At the same time I volunteered as Vice Chair of the Chancellor's Advisory Committee on Disability at UCLA. We worked on the various problems facing the disabled community on campus. I thought that I had some free time, so I was also the manager of my apartment building.



### CURRENT RESIDENCE:

Somerville, Massachusetts

### HOMETOWN:

Newton, Massachusetts

### HOBBIES:

Traveling, definitely traveling. Learning foreign languages, reading, watching movies from the 60s, spending time with my east-coast friends and family now that I'm back in the area, re-exploring Boston.

### IDEAL VACATION SPOT:

That is definitely Peaks Island, Maine. It is beautiful, quiet, and woodsy, with great views of an island-spotted horizon. It's the only place I know where there is no traffic, I can take walks late at night, and the lack of light pollution allows for breathtaking views of the night sky.

### IF YOU COULD DO ANYTHING IN THE WORLD, WHAT WOULD IT BE?

Fly. I would love to fly freely, with nothing holding me up and nothing pulling me down.

# THE BOSTON CURE PROJECT

## PILOT BLOOD, TISSUE, AND DATA BANK

By Art Mellor

Over the past year we've devoted a lot of time to creating a major new resource for the scientific community – a large-scale MS blood, tissue, and data bank. Now that we're on the verge of collecting the first samples, we wanted to share our motivation for doing this, describe our journey to this point, and preview how the bank will operate.

**Why this bank is needed:** Multiple Sclerosis (MS) has two characteristics that make it particularly difficult to address using traditional methods of medical research. These characteristics are not unique to MS and are probably shared with many of the major diseases we are struggling to understand, such as diabetes, heart disease, and rheumatoid arthritis.

The first characteristic is that MS is most likely a multifactorial disease. This means that its underlying cause is not a single agent such as a gene, a pathogen, a toxin, a nutritional imbalance, or some sort of trauma. Rather, research suggests that a combination of factors is at play. For example, people with MS might have a genetic susceptibility (possibly involving a number of genes) that requires an environmental trigger (like a pathogen, toxin, or stress) to initiate the disease processes that lead to MS.

This characteristic implies that in order to understand the causes of MS we will need to have researchers from different disciplines studying the same individuals. Most medical researchers concentrate in one specific area and are not facile in multiple domains. This is largely a function of the amount of information needed to master even a single discipline. Thus geneticists, toxicologists, virologists, etc., usually conduct completely separate studies focused on their own disciplines. These studies are usually based on separate groups of subjects, so the results of different studies cannot be combined to find cross-discipline relationships.

The second characteristic is that MS may very well be a family of diseases with the same end-point, as opposed to a single disorder. The set of root causes for one person with MS may be quite different from those involved in another. This implies we need to study very large populations of people in order to have meaningfully sized subsets of people with the same underlying causes. A study with 100 people with "MS" might actually have 20 people with each of 5

different forms of MS – making it quite difficult to find the patterns necessary to determine the causes.

To address these characteristics, the Boston Cure Project has embarked on a mission to create a large-scale, multidisciplinary, blood, tissue, and data bank. This resource will include a large number of samples collected from people with MS and unaffected matched controls, and will be made available to scientists working to determine the causes of MS.

The samples will be collected and processed in a variety of ways so that many different types of analyses will be possible. Each sample will also have corresponding medical records and epidemiological data. In exchange for access to samples, researchers will return the data generated from their analysis to be shared with others who use the samples in the future.

One question that may spring to mind is: Why haven't scientists already set up something like this? The concept isn't visionary and it is largely accepted as the right way to proceed, but it does contain three major stumbling blocks: 1) It is expensive, 2) it is administratively difficult, and 3) it isn't publishable. Any one of those three would dissuade an individual scientist since researchers are responsible for raising their own funds, doing research, seeing patients, training fellows, and publishing papers. That's why a nonprofit like the Boston Cure Project is the ideal place to make something like this happen. We can raise significant amounts of money, we have the time to deal with the administrative difficulties, and we don't need to worry about publishing!

**Making it happen:** In order to demonstrate feasibility we are starting this effort with a pilot study in which we will collect a total of 100 samples at 2 hospitals in Massachusetts. (Once this study has commenced, we will design a follow-on study to collect 1,000 samples at a number of centers around the country.)

Thankfully we have almost completed the protracted planning process necessary to launch the pilot. It has taken far longer than we ever expected! We started by contracting the services of Genomics Collaborative, Inc. (now a part of SeraCare), a commercial tissue banking facility. This allowed



us to avoid the huge up-front capital expense of freezers, lab equipment, computers and so on that are needed to operate a tissue bank. Genomics Collaborative (GCI) will be responsible for sending out blood draw kits to the study clinics, processing and storing the samples, and distributing the collected samples and data to scientists at our direction. GCI helped us design the study protocol (the instructions on how the study will be performed) based on extensive experience doing similar studies for other diseases. They also helped us create a questionnaire to collect personal health and history data from participants, as well as a disease ascertainment form to document how the diagnosis of MS was made in affected subjects.

We then worked with our pilot study sites, the Beth Israel Deaconess Medical Center and the University of Massachusetts Medical Center, to create Informed Consent Forms (ICFs) which are the lay-person's description of the study that each participant will sign. Once all the study-related documents were completed, we had to submit them to the Institutional Review Boards (IRB) at both of these hospitals. The IRB is a group of physicians and community members who ensure that all human research at a given institution meets its ethical standards. We received IRB approvals from both hospitals, freeing us to begin negotiating the agreements and budgets that are needed before we can collect blood and data. At the time of this writing we are in the final stages of this process at both institutions; once the agreements are in place we can begin collecting samples.

**How the collection will work:** People who come to either of these institutions for their regular neurological appointments will be told about the study and asked if they would like to participate. They will be given materials to review and will make a study appointment if they decide to participate. At the study appointment they will have a quick review by their neurologist, have their blood drawn, and be asked the questions on the questionnaire. If they have first degree blood relatives (parents, siblings, or children of 18+ years) who don't have

MS and who might be interested in participating as a control, they will be asked to mention the study to them.

All samples and data will be anonymized and barcoded to protect the privacy of the participants before being sent to Genomics Collaborative to be processed and stored. Links from the barcodes to the subjects and family controls will be stored for a time at the hospital (to allow for follow-up questions) and then sent to the Boston Cure Project.

Once a sufficient number of samples has been collected, we will begin making them available to researchers working on determining the causes of MS. The researchers will be

required to return the data they generate from the samples (after a reasonable time period to allow them to publish their results) so that it can be shared with other researchers in the future.

**Looking ahead:** As soon as the pilot collection is underway, we will begin designing the follow-on study. This study will not only involve a much larger number of participants and a wider variety of controls, but we may also expand the sample types collected to include cerebro-spinal fluid (CSF) and post-mortem brain tissue. Also, although the pilot study is a one-time collection, the

follow-on study will involve contacting participants on a yearly basis to collect additional samples and information, so that we can track how MS subjects and controls change over time.

All of the documents described in this article are available for download in PDF format at the bottom of this page of our web site:

<http://www.bostoncure.org/curemap/tissuebank.php>

Just click on the title of the document you wish to download.

If you would like to stay informed as to the status of this effort, including future collection sites, please sign up for our mailing list at:

<http://www.bostoncure.org/about/joinemail.php>

**Once a sufficient number of samples has been collected, we will begin making them available to researchers working on determining the causes of MS.**

# CURE MAP UPDATE

Through the efforts of two summer interns from MIT, we are making quite a lot of progress on the Phase 1 documents covering toxic agents and nutrition. Irene Rahman, a junior majoring in Biological Chemical Engineering, is developing a framework for analyzing toxic agents and their role in human disease. Brian Keegan, a junior and a Mechanical Engineering major, is creating a similar framework for nutritional deficits and imbalances. By the end of the summer these documents should be complete, at which point we'll be able to use them to analyze potential toxic and nutritional causes of MS. We'll notify our mailing list as soon as these documents are finalized and available on our web site.

The Phase 2 analysis of infectious agents as triggers of MS is also fully underway. Hollie Schmidt, VP of Scientific Operations, is compiling a spreadsheet listing the laboratory and epidemiological studies performed so far to investigate potential infectious risk factors for MS. She is also analyzing each pathogen in turn to weigh the evidence regarding its involvement in MS.

## VOLUNTEERS

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

### VOLUNTEER STAFF

Susan Mellor –  
Administrative Assistant  
Stephanie Sisto – Intern

### ACCOUNTING

Debbie Frattaroli  
Jill McGaffigan

### ADVISORS

Gabe d'Anunzio  
David Hirschberg  
Bill Ray

### APPEAL MAILING

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Marion Carroll

### CUTS TO CURE MS

Janelle Hamilton

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Deborah Kearney  
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George Peabody

### GOLF 2004

Deborah Kearney  
Jacqui McCoy  
Mark Aher

## LABRYINTH

Lisa Desautels  
Jill Tagliaferri

## MS SOCIAL

Rosalind Joffe  
Gail Martino  
Susan Morissette

## NEURO NEWSLETTER

Jennifer Frashure

## NEWLY DIAGNOSED BOOKLET

Maggie Harling  
Cynthia King  
Lisa Paine

## NEWSLETTER

Barbara Morgenlender  
David Morgenlender  
Carol Rose  
Lisa Sargeant

## OFFICE MOVE

Alex Collingridge  
Ray Desautels  
Michael Haag  
Leslie Kenney  
Debbie Mellor  
Anthony O'Shea  
Lisa Sargeant

## SCAVENGER HUNT 2004

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Andy Brown  
Kathleen Chantliou  
Joan Coyne  
Elizabeth Dean-Clower, M.D.  
Karen Freeman  
Bryan Gildeberg  
Nancy Gildeberg  
Katy Hill  
Kimberly Labow  
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Alyssa Mades

Daniel Mades  
David Mades  
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Ellie Mirman  
David Olson  
Brad Parker  
Alicia Penny  
Michael Pomarole  
Chuck Potier  
Fiona Reardon  
Rachel Elias Rekha Koshy  
Susan Rowe  
Shannon Sardelli  
Lisa Sargeant  
Sabrina Sequiera  
Frank Sisto  
Amanda Song  
Kevin Song  
Suzie Truglia  
Lori Tsuruda  
Belinda Vandervoort

## TISSUE BANK FLOW CHART & METRICS

Julia Chang  
Dave Kuo

## OTHER

Theresa Hahn (*staff party*)  
Susan Jones (*Genetic Spreadsheet*)  
Robert Lester (*LDN Project*)  
Evin Luongo (*MIT appeal, administrative assistance*)  
Debbie Mellor (*raffle*)  
Bill Meyer (*PR*)  
Stephanie Sisto (*MS research spending analysis, MIT appeal*)  
Jennifer Tobin (*Neuroanatomy Paper*)

## PEOPLE AND COMPANIES CONTRIBUTING GOODS OR SERVICES:

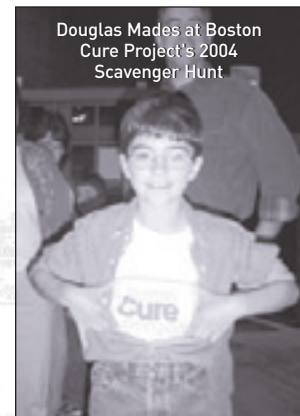
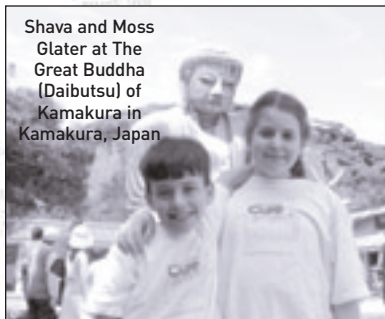
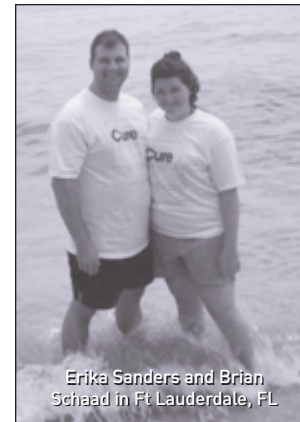
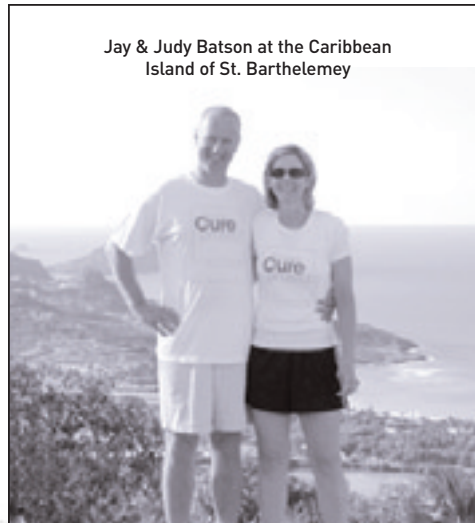
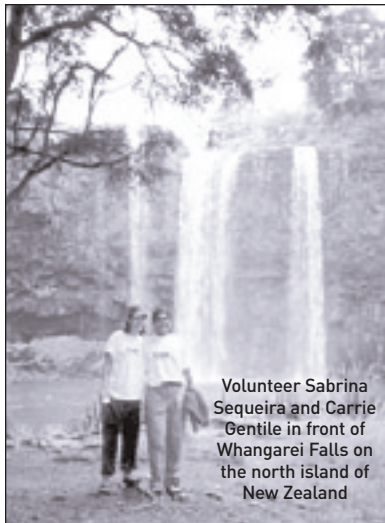
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If for any reason you've been left off this list in error, please let us know so we can include you in our next issue!

# 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!



## BOSTON CURE PROJECT: IN THE NEWS

We've had a lot of press coverage lately. Here are some places you can see Boston Cure Project mentioned (also available at <http://www.bostoncure.org/news/bcp.php>)

*Searching for a Cure: Boston Cure Project Implements MatchPoint* by Kinley Levack  
[www.Econtentmag.com](http://www.Econtentmag.com)  
06/04/04

*Taking on MS: A War on Multiple Fronts* by Jennifer Huget  
*Washington Post*, Page HE05  
06/01/04

*Lucky Magazine*, Page 266  
05/01/04

*Mapping a Cure* by Elizabeth Durant  
*Technology Review, MIT Supplement*, Page 15  
04/01/04



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contact information to  
[newsletter@bostoncure.org](mailto:newsletter@bostoncure.org)  
or give us a call at  
781-487-0008!

### Change Service Requested

#### 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, 300 Fifth Avenue Waltham, MA 02451*

**By Credit Card:** on [www.bostoncure.org](http://www.bostoncure.org), click on the "Contribute" box at the top of the page and follow instructions under the heading "Contributions by Credit Card."

**Volunteer Today:** See [www.bostoncure.org](http://www.bostoncure.org) for volunteer opportunities. On the left click "About," then click "Volunteer," then click on any of the volunteer opportunities for more details. You may also call 781-487-0008 or email [info@bostoncure.org](mailto:info@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.** Call 781-487-0008 or email [info@bostoncure.org](mailto:info@bostoncure.org)

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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. Access to the site is available free of charge by visiting [msnews.bostoncure.org](http://msnews.bostoncure.org).

#### Have you moved? Changed your email address?

Let us know! Send changes in contact information to [newsletter@bostoncure.org](mailto:newsletter@bostoncure.org) or give us a call at 781-487-0008!

#### BOSTON CURE PROJECT UPDATE VOL. 3 – SPRING/SUMMER 2004

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Rich Macaluso of Mail Perfect, Inc. ([www.mailperfect.com](http://www.mailperfect.com))

Editor-in-Chief: Julie Morgenlender

Writers: Art Mellor, Julie Morgenlender, Melissa, O'Shea, Lisa Sargeant, Hollie Schmidt

Editors: Barbara Morgenlender, David Morgenlender, Julie Morgenlender, Carol Rose, Hollie Schmidt

Photographers: Art Mellor and David Morgenlender

This newsletter available online at [www.bostoncure.org](http://www.bostoncure.org), in the "Downloads" section.