

## BOSTON CURE PROJECT'S PILOT BLOOD, TISSUE, AND DATA BANK HAS BEGUN

**B**oston Cure Project's first blood sample for its pilot Blood, Tissue, and Data Bank has been collected. On September 1, 2004 Boston Cure Project founder, President and CEO Art Mellor provided the first sample at UMass Memorial Medical Center in Worcester, MA, officially starting our sample collection efforts. This is a pilot involving the collection of a total of 100 samples in order to debug the process and demonstrate feasibility. We will take what we learn from this process and roll it into a follow-on study to collect thousands of samples nationwide.

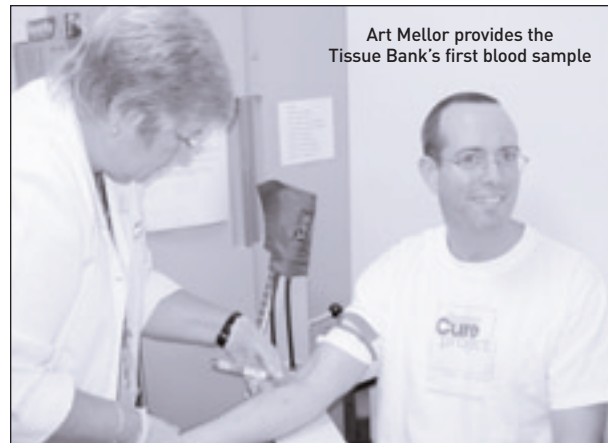
Boston Cure Project's Blood, Tissue, and Data Bank, one of the largest such banks for Multiple Sclerosis, will enable researchers from different disciplines to access the same blood samples, giving them the ability to collaborate in a manner not previously available.

As of September 1, 2004 we have two hospitals online: UMass Memorial Medical Center and Beth Israel Deaconess Medical Center. We received ethical review approval via the Institutional Review Board at each facility and negotiated a contract for financial arrangements with each hospital. We are now recruiting subjects.

People are recruited into the study when they come to one of these facilities for an appointment with a neurologist. The neurologist assesses whether the person fits the criteria established for the protocol and tells them about the study. If they are interested, they are given materials to review and are told how to make an appointment for a study visit. They are also asked if they would like to contact certain blood-related family members not afflicted with MS to serve as controls for them in the study. This is optional and the only contact is through the study participant with MS.

On the day of the study visit, the study staff obtain informed consent from the participant and answer any questions. A confidential contact sheet (CCS) is filled out that will allow the sample collected to be linked to the person, so we can ask to replenish it at a later date, if necessary. A participant unit form (PUF) is started to link this person with any relatives that may later participate as controls.

The neurologist will see the person and fill out a disease ascertainment form that will record the clinical and lab test results that resulted in the diagnosis of MS. The study coordinator will then go through the extensive questionnaire with the person and fill out a formal copy.



Art Mellor provides the Tissue Bank's first blood sample

Three vials of blood will be drawn by the study coordinator or other authorized person. The tubes, all pages of the questionnaire, the CCS, and the PUF are all tagged with a bar code unique to this person. The entire process will take the participant around 2 hours. The blood, the questionnaire, and applicable lab results are delivered to the tissue repository, Genomics Collaborative, Inc. The CCS, and eventually the PUF are sent to Boston Cure Project.

Once received by Genomics Collaborative, the blood is checked for quality, processed for storage and sent to freezers. The data is checked for completeness and then entered into the database. If there are any questions, the physician is contacted and asked to resolve them with the participant. After six months or at the study's end end, any records linking the person to their bar code at the physician's office are destroyed. Samples and data given to researchers (or Boston Cure Project) are stripped of bar codes and have separate unique IDs inserted which are generated by Genomics Collaborative to ensure participants' privacy.

## LETTER FROM THE PRESIDENT

In this issue we are announcing a major accomplishment - we collected our first sample for our pilot trial for the blood, tissue, and data bank! We also explain in detail what is involved in the trial.

In addition we have an article on how an MRI works, news of the very successful Golf Tournament and Labyrinth Walk events, a profile on volunteer Amanda Song, and as always, more Boston Cure Project T-Shirt pictures from around the globe.

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.**



# YEAR END GIVING

## ... IT HELPS US AND IT HELPS YOU!

### YEAR END TAX DEDUCTIONS

Hard to believe, but yet another year is drawing to a close. We would like to remind you that, if you have not yet made a contribution to the Boston Cure Project, now is a great time to do so. Make your gift before December 31 and you'll do so in time to claim it as a deduction on your next round of tax returns.

### HOLIDAY GIFT GIVING

If you're searching for a unique and thoughtful gift for someone special this holiday season, then consider Boston Cure Project before you hit the malls. Perhaps you or someone you know would prefer that family and friends donate to a worthy cause in lieu of giving gifts.

You can make a gift to the Boston Cure Project in honor of, in name of, or in memory of any individual you choose. Simply contact Boston Cure Project and tell us how and to whom you would like your gift dedicated. We will send a special letter to that person informing them of your generosity. Gifts of \$250 and above will appear in our annual report.

Don't forget that many companies also look to its employees at year-end for recommendations on charities to whom they might award a corporate gift. Check with your employer or Human Resources department to see if your company makes year-end charitable contributions and whether or not the Boston Cure Project would qualify for support.

For more details about how to make a gift, contact our Development Director, Melissa O'Shea, by email at [melissa@bostoncure.org](mailto:melissa@bostoncure.org) or by phone at 781-487-0011.

# SECOND ANNUAL “TEE OFF TO CURE MS” A SWINGING SUCCESS

**O**n Monday, July 12th, eighty golfers teed off to cure MS at the Boston Cure Project's second annual golf tournament. This year's event took place at Charter Oak Country Club in Hudson, Massachusetts on the club's 6,950-yard, 18-hole championship, beautifully designed golf course.



Scramble winners

An excellent course, wonderful weather, and a great cause combined to make it a memorable and successful event. The event raised over \$19,000 in profits for the Boston Cure Project's work in determining the causes of Multiple Sclerosis.

Organized entirely by volunteer supporters Jacqui McCoy and Mark Aher, the tournament drew support from twelve corporate sponsors: Bain Capital – Sankaty Advisors, General Dynamics, Mellon Bank, Paul | McCoy Family Office Services, Marsh Private Client Services, O'Shea Tours, ITSMA, Boston Federal, Goldwasser Appel Insurance Advisors, Diametric Marketing, North Bridge Venture Partners, and TJX Foundation.



Best Ball winners

Thanks to sponsor, North Bridge Venture Partners, the driving range and putting green were available at 10:00am. Teams turned up to register, pick up their gift bags, get in a few practice swings and then headed off in their carts.

A shotgun sounded at noon to start the tournament. Teams had the choice of participating in a best ball format or a scramble competition. Other fun challenges and contests took place, including a competition for both the men's and women's longest drive and a hole-in-one contest sponsored by Long Motors of Framingham. A red Hummer was parked out on the 17th hole as reward for a hole in one. None were made, but several came close.

At the end of the tournament, the winners of the best ball competition were Mark Aher, Jim Aher, Patty Horn and David Valletta. The scramble winners were Dan Allen, Bob Dillon, Tom Kirchmaier, and Vic Lanio.



[From Right] Organizers Mark Aher and Jacqui McCoy with staff Melissa O'Shea and Julie Morgenlender

*Congratulations to all!*

A shoot-out also took place among the three individuals who got closest to the pins on three designated holes and two randomly chosen players. Bob Joy was the shoot-out winner, taking home a set of Titleist forged stainless 704.CB irons as his prize.

Following the event, Charter Oak hosted a beautiful meal in the ballroom and an auction took place featuring a range of sports and movie memorabilia.

Plans for next year's event are currently underway, so watch for more details. If you like to golf and want to be involved, please let us know. Reserve your spot now or get your company involved as a sponsor 781-487-0008.

Boston Cure Project extends a big thanks to Mark and Jacqui for their tremendous contribution of time and effort. The event would not have been possible without them. Thanks also to all of our generous sponsors, participants, and volunteers who made the event such an overwhelming success. We look forward to seeing everyone again next year.

# MAGNETIC RESONANCE IMAGING

## IN MULTIPLE SCLEROSIS

By Hollie Schmidt

One of the greatest challenges in studying Multiple Sclerosis is that the site of the disease is so inaccessible. Not only is the **central nervous system (CNS)** physically protected by the skull and spine, but its vulnerability to injury coupled with its importance in the body deter us from gaining access to it unless absolutely necessary. Still, without knowing what MS is doing in the brain and spinal cord, how can we hope to understand this disease and find ways to combat it?

Fortunately, there are ways to learn about what is taking place inside the CNS without physically invading it, and they are getting more sophisticated all the time. In MS the best technique for studying the central nervous system is **magnetic resonance imaging (MRI)**. Nowadays MRI is a standard part of diagnosing MS and is often used in ongoing clinical care as well, to evaluate disease progression (because not all changes in the brain produce noticeable symptoms) and treatment effectiveness. It is also used in drug treatment trials to determine a drug's effect on lesions, and in other types of research to help scientists better understand how MS develops. All in all, it's extremely useful from a number of standpoints and therefore worth understanding. Don't let the complicated-sounding technology and the technical jargon scare you! This article will explain in simple terms how MRI works, how it's used in MS, and what new developments are in store.

### THE BASICS OF MRI

MRI is based on just a few simple principles of electricity and magnetism. If you've ever studied physics in school, you may remember that a magnetic field moving relative to a coil of wire can generate an electrical current in the wire. We can measure the current and use those measurements to understand the magnetic field that produced it. If the motion of the magnetic field changes, so will the current in the wire, and the change in current can in turn tell us about the changes in the magnetic field.

MRI makes use of these principles to allow us to study various properties of the body. In MRI, the magnetic fields that we're interested in are the tiny ones produced by the single protons in the centers of our hydrogen atoms. Hydrogen atoms are useful to study because they are plentiful in the body and found in many molecules of interest such as water and fat. Our protons are constantly spinning, and this motion generates magnetic fields which are normally pointing in all different directions. Using an MRI machine, we can line up the spins and magnetic fields of these protons along a specific direction. This is done by first turning on a very powerful magnet, which aligns the protons' spin and magnetic fields with its field, and second, activating a **radiofrequency (RF)** coil, which transmits waves of energy to the protons, causing them to tilt in a new direction and rotate in unison. The com-

bined magnetic fields from these energized, tilted, rotating protons will generate an electrical current in a properly positioned wire receiving coil. This current can be detected and measured, which comes into play in the third step.

When we then turn off the radio waves that are energizing the protons, each proton will transfer its absorbed energy to its environment and go back or "relax" to its original state where its magnetic field is lined up with the main magnetic field and where it is no longer rotating in unison with the other protons. However, not all protons relax at the same rate because some environments are quicker than others to absorb the released energy. For instance, protons in fatty tissues such as myelin tend to relax more quickly than those in watery tissues like cerebrospinal fluid.

As the protons relax to their original orientation, their ability to generate electricity in the coil weakens. Again, how fast this happens depends on the protons' local environment. So by studying the electrical flow in the coil after the radio waves are turned off, we can tell things like what type of environment those protons are located in and how closely they're packed together.

In essence, that is how MRI is used to analyze tissue properties. In an actual MRI machine there are additional important mechanisms and controls. For instance, in addition to the main magnet and the radiofrequency coils, MRI machines also have gradient coils that are used to localize the signal so that we can image specific points in the body. Also, there are computers that not only control the various machine components but also process the signals from the receiving coil and translate them into the 2-D and 3-D images you may have seen.

### T1, T2, GD, AND OTHER MRI VARIETIES

There is not just one single technique for acquiring or analyzing an MRI image but rather several methods that provide different types of information. Here's a quick overview of some of these techniques, starting with a few that are currently used today in diagnosing and monitoring MS.

Some techniques involve modifying imaging parameters to generate specific types of images. For instance, by adjusting the timing of the imaging steps we can generate images that are **T1- or T2-weighted**, depending on whether we want to analyze the rate in the relaxation process at which protons align back with the main magnetic field (T1) or the rate at which they lose their tilt (T2). Both of these methods help show lesions in white matter because lesions provide a different environment than normal fatty white matter when it comes to facilitating proton relaxation. In a T1-weighted image, a hypointense or dark area (black hole) indicates loss of tissue and persistent axonal dam-



age, whereas in a T2-weighted image, a hyperintense or bright area shows acute or chronic damage.

Other types of images are generated with the use of contrast agents that have special magnetic properties. These are injected into the body to help highlight areas of interest. The most common contrast agents used in studying MS are those containing the magnetic element **gadolinium (Gd)**. Normally the blood-brain barrier prevents Gd from entering the brain, but this barrier can be disrupted where there is inflammation, allowing Gd to leak in. Therefore, Gd can be used to find inflammatory lesions in T1-weighted MRI images. Gd compounds are comparatively highly magnetic, which speeds up the relaxation of surrounding water molecules, and thus areas that contain Gd show up on MRI as bright regions.

In addition to these standard types of measurements, a number of newer techniques are used in research settings and may someday also see regular use in the clinical diagnosis and monitoring of MS. For instance, in addition to identifying lesions, MRI images can be used to estimate how much of the skull contents are brain tissue versus cerebrospinal fluid. This gives an indication of how much shrinkage, or atrophy, has taken place in the brain or spinal cord. One form of this volume-based measurement commonly used in research is **brain parenchymal fraction (BPF)**.

In **magnetic transfer imaging (MTI)**, the timing parameters are adjusted to maximize the signal from “bound” protons (e.g., those in proteins or other large molecules) relative to free protons in water. Comparing this image with a non-adjusted image to generate a **magnetic transfer ratio (MTR)** can reveal information about lesions such as degree of severity. MTR has also shown the presence of lesions in **normal appearing white matter (NAWM)** as well as abnormalities in gray matter.

**Diffusion tensor imaging (DTI)** analyzes whether water molecules in a tissue can move about or diffuse easily (expressed as “mean diffusivity”), and whether they can diffuse in all directions equally well or only in certain directions (“fractional anisotropy”). White matter is normally very directional due to the long bundles of axons running through it, but where the tissue is disrupted as in lesions or other damaged areas, fluid is freer to diffuse in different directions. Therefore, DTI is a useful technique for analyzing lesions and finding NAWM anomalies.

A technique that analyzes the biochemical components of tissue rather than its structural qualities is **magnetic resonance spectroscopy (MRS)**, which can detect the presence of certain molecules. In the brain, MRS can measure the presence of

**N-acetyl aspartate (NAA)**, a compound normally found in axons. A decrease in NAA levels in a region can be a sign of axonal loss or dysfunction. Other molecules that are associated with myelin or astrocytes can also be analyzed using MRS. In MRS, the waves generated by the RF coil are tuned to a frequency that will excite only specific nuclei (e.g., phosphorus nuclei); the resulting signal gives a spectrum of the frequencies of the different molecules containing that atom.

Finally, **functional MRI (fMRI)** is a technique used for studying which areas of the brain are active when a person is carrying out certain tasks that involve thinking, looking, feeling, or moving. fMRI identifies areas in the brain where blood flow and oxygen levels are increased, indicating activation. In MS, fMRI is helping to reveal how the brain adapts to injury by recruiting alternate neural pathways to perform tasks.

#### WHAT'S NEXT IN MRI?

It is fair to say that MRI has already vastly enhanced our understanding and management of MS and promises to do even more for us in the future. Still, as with any technology, there is always room for improvement! One area where MRI technology is likely to get a boost is in the strength of the main magnetic field. MRI machines in clinical settings typically use a main magnet that is 0.5 to 3.0 Tesla; however, higher strength magnets can increase the resolution of the images produced. So we may soon see magnets in everyday use that go up to 7 Tesla or higher. (To put this in perspective, a typical magnet on your refrigerator has a field of just one-hundredth (.01) Tesla.)

Another development in MRI research is the use of agents that can be used to label specific types of cells, such as **ultra-small paramagnetic iron oxide (USPIO)** molecules. USPIO molecules, when injected in the blood stream, are taken up by cells called macrophages that engulf foreign materials and debris. Like gadolinium, USPIO can be visualized on MRI and therefore the presence of USPIO on an image of brain tissue indicates where a macrophage has passed through the blood-brain barrier. Use of this type of technology could be very useful in understanding how, when and where certain cells are moving into the central nervous system, enhancing our knowledge about the sequence of events in MS.

For more information on the physics and uses of MRI, visit these on-line resources:

**Basic information:**

<http://electronics.howstuffworks.com/mri.htm>

**Technical information:** <http://www.erads.com/mrimod.htm>

**MRI in MS (with images):**

<http://www.emedicine.com/radio/topic461.htm>

## VOLUNTEER PROFILE: AMANDA SONG

**NAME/NICKNAME:**

Amanda

**JOB/OCCUPATION:**

Software Engineer for Nokia

**CURRENT RESIDENCE:**

Belmont, MA

**HOMETOWN:**

Cheyenne, WY

**INVOLVEMENT WITH BCP:**

Volunteered as the Day of Event Director for the 2004 Scavenger Hunt, currently volunteering as the Day of Event Director for the Sing to Cure MS Halloween Concert.

**HOBBIES:**

Besides volunteering for the BCP...being a Big Sister to an awesome Little Sister, Mercedes, through Big Sisters of Greater Boston, bicycling, running, reading books for book club, baking

**IDEAL VACATION SPOT:**

A small island that sits far enough away from the mainland as to make the stars light up the sky at night with a rustic and cozy beach house (no TV or phone) that sits on a beach that is perfect for snorkeling.

**FAVORITE MOVIE OR BOOK:**

Movie: Mostly Martha,

Book: Dandelion Wine by Ray Bradbury

**LEAST FAVORITE THING:**

Sitting in traffic

**MOST FAVORITE THING:**

Kevin\*

*\*Editor's note: Kevin is Amanda's husband.*

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

Besides help cure MS? Travel the world for a year.

## CONGRATULATIONS CORNER

Congratulations to Boston Cure Project intern Stephanie Sisto on her graduation and new job. After researching and analyzing spending in MS organizations for Boston Cure Project, Stephanie received her Master's Degree from Simmons College and now works at Tufts Healthcare.

Congratulations to Janelle and Brian Hamilton of Norfolk, VA on the birth of their new daughter, Peyton. Brian and Janelle own About Face Hair Salon of Norfolk, VA, and, with the support of their generous staff and customers, run the Boston Cure Project's annual "Cuts to Cure MS" cut-a-thon.

Member of Boston Cure Project's Pharmaceutical Advisory Board Koby Mok recently gave us the good news that he recently got married.

Congratulations to Koby and Audrey!

## LABYRINTH WALK

If you're like most people, you may think you know what a labyrinth is. Most of us assume it is a maze. However, unlike a maze, a labyrinth has only one path. There are no tricks to it and no dead ends. There are no high walls. The path of a labyrinth simply winds peacefully on the ground, giving those who walk it a chance to relax and meditate.

On Saturday, September 18th, Boston Cure Project volunteers, Jill Mackavey and Lisa Desautels, organized our most relaxing fundraiser ever. A labyrinth walk took place at the Andover-Newton Theological School in Newton Centre, Massachusetts. A 36-foot canvas labyrinth was laid out for participants to walk upon and inwardly reflect. Light refreshments were served throughout the day and Jill, a Certified Labyrinth Facilitator, spoke about the labyrinth, introducing us to its history, applications, and benefits. In addition to the canvas labyrinth, there were a few smaller, handheld, tabletop labyrinths for those with limited mobility or vision impairment. Harpist, Christine Tulis, also played beautiful, soothing music to suit the mood.

Lisa and Jill organized the event with the belief that the meditative qualities of a labyrinth can help those affected by MS and their family and friends find new reserves of courage, patience, and peace of mind. It was open to children as well as adults and the cost was \$25 to attend.

Lisa and Jill raised more than \$2,000 for the Boston Cure Project through this effort and those who attended spoke highly of the experience. Thanks go to Lisa, Jill, and all who participated.

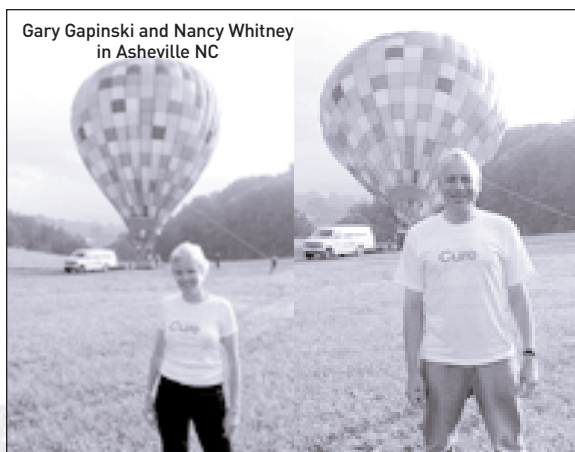
# T-SHIRT PICTURES

## 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!



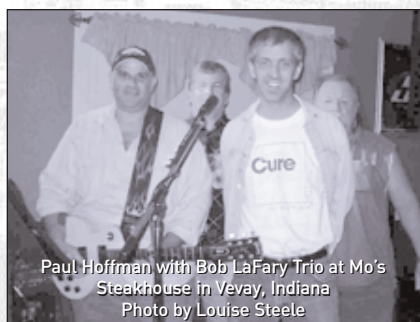
Asha Mellor banding geese in the arctic  
Photo by Tony



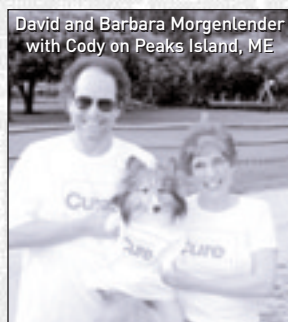
Gary Gapinski and Nancy Whitney in Asheville NC



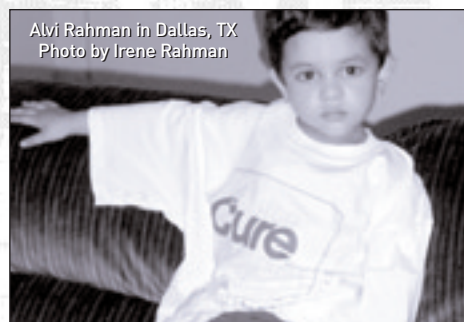
Samson Mellor taking a closer look at the golf tournament tote bags  
Photo by Art Mellor



Paul Hoffman with Bob LaFary Trio at Mo's Steakhouse in Vevay, Indiana  
Photo by Louise Steele



David and Barbara Morgenlender with Cody on Peaks Island, ME



Alvi Rahman in Dallas, TX  
Photo by Irene Rahman

## VOLUNTEERS

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

### VOLUNTEER STAFF

Susan Mellor – Administrative Assistant  
Stephanie Sisto – Intern

### ACCOUNTING

Jill McGaffigan

### BOSTON CURE PARTY TO CURE MS

Debbie Mellor  
Bill Meyer  
Ellie Nelson

### CRUISE TO CURE MS

Judy Medeiros

Nancy Medeiros  
Irene Simas

### CUTS TO CURE MS

Sarah Conklin  
Janelle Hamilton

### DONOR DATABASE

Joan Coyne  
Dave Kaffine

### FUNDRAISING

Ray Desautels  
Melanie Erickson  
Bill Hecht  
David Lekis

### GENOME SPREADSHEET PROJECT

Susan Jones

### JULY APPEAL

Barbara Morgenlender  
Stephanie Sisto

### LABYRINTH WALK

Lisa Desautels  
Ray Desautels  
Jill Mackavey

### MIT APPEAL

Brian Mellor  
Anna Peabody

### NEWSLETTER

Patrice Connelly  
Lisa Desautels  
Daniel Pelletier, M.D.  
Marie Rudzinsky

### PR

Deborah Kearney  
Bill Meyer

### SING TO CURE MS

Marion Carroll  
Lisa Desautels  
Rebecca Enright  
Ruth Seidman

Amanda Song

### TEE OFF TO CURE MS

Mark Aher  
Deborah Kearney  
Jacqui McCoy

### OTHER

Gabe d'Anunzio (Marketing)  
Brian Del Vecchio (MSNews)  
Roger Glovsky (Legal Services)  
Brian Mellor (Rita Glaze Mailing)  
Jen Tobin (Neuroanatomy Paper)

### PEOPLE AND COMPANIES CONTRIBUTING GOODS OR SERVICES

Clockwork Design Group, Inc.  
Art Mellor

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!



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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!

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