



MULTIPLE SCLEROSIS update

(VOL. 4 : SUMMER 2005)

INSIDE

Letter from the President2



The Not-So-Average Birthday Party3

The African American Multiple Sclerosis Genetics Project at UCSF4-6

Donor Profile5

Employee Profile . . .6



Starfish Inspire Expansion Team from North Carolina7

Calendar of Events .7

Hunt to Cure MS Finds Entertainment for All

Boston Cure Project’s fourth annual Scavenger Hunt to Cure MS brought together 19 teams and more than 40 volunteers to create a fun event which raised more than \$38,000 to find the causes of MS.

This year’s hunt was directed by Lisa Sargeant with a core team of volunteer directors: Amanda Song, Nancy Medeiros, Nancy Costello, Debi Robison, Stephanie Sisto, Lily Towers, Sue Mellor, and Debbie Mellor.

Prizes were given to the first, second, and third place winners in each of three categories: the team who raised the most money, the individual who raised the most money, and the team who earned the most points. The winners of the first two categories were YWMSB (Young Women with MS in Boston) and Jennifer Kulm. The team who won the Scavenger Hunt with 1555 points was California Street Associates. The team’s leader, Rachel Elias, gives us her perspective on the day:

“The Hunt to Cure MS was an absolute blast! We had so much fun. I still can’t believe we held a live rooster and found an actual newspaper article from President Lincoln’s assassination.



“Our team, California Street Associates, was named after the street we all grew up on or near. We decided to participate in the Scavenger Hunt since our team members are all competitive by nature and enjoy a challenge for a worthy cause. I knew we were off to a exciting start when we literally ran out the door of the Skellig with the list in hand - there was no time to waste! Our plan was simple: we listed each item from the list in sequential order, then we listed locations where we could find those items. For example, The Library: National Geographic Magazine #15 & Autobiography/Star Trek Actor #26. We did have a few surprises, such as at the Newton Cemetery where we expected to find a “big hand” on one of the grave sites only to learn from the grounds-keeper that it was stolen last year!

(continued on page 2)

Letter from the President



In this update we are pleased to tell you about a new team member, our accelerating volunteer efforts, and an important MS genetics program.

We're happy to announce the addition of Sarah Nels as Event Manager. She'll be handling the oversight of all of our events and volunteer efforts which will free up Melissa to concentrate on major gifts. You can read about her here and see her bio on our web site in the About->People->Staff section.

Our volunteers are on the move helping spread the word and raise funds. Some of their work is profiled in this update including efforts by the Low County MS Cure Fund, Sean Reardon, the Yashko Family Fund, and our annual (volunteer-run) Hunt to Cure MS scavenger hunt.

The University of California San Francisco has some of the most dedicated and capable MS researchers in the world. Dr. Jorge Oksenberg, who heads up MS genetic research there and is a member of our scientific advisory board, describes their research program and one of their current projects which is seeking participants. We hope you enjoy reading about their efforts and consider getting involved in their work.

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.acceleratedcure.org.

Regards,

Art Mellor
President & CEO
art@acceleratedcure.org

Hunt to Cure MS Finds Entertainment for All

(continued from page 1)



"When we arrived back at the Skellig we had a big bag of loot and no idea how well we had done. After the judges told us we were one of the four finalists we jumped up and down with excitement. The adrenaline was rushing! At that point we were asked to come up on stage and cheer for an

extra 50 points to win the Hunt. Our cheer was simple yet effective: 'S-U-C-C-E-S-S, Boston Cure fights MS! V-I-C-T-O-R-Y, victory, victory that's our cry!' We are absolutely going to do the Hunt again next year."

Thanks to our many prize and service donors - too many to mention here - and to our many wonderful volunteers who helped organize this year's hunt with pick-ups, deliveries, poster distributions, follow-up calls and other tasks. Special thanks also go to

Jennifer Kulm, Robin Farren, Bill Myer, and our head judges Michael and Timothy Pomerole. We also thank the Minassian and Gildenberg families for all of their support as well as John Hancock LTC Community Service Program Volunteers who assisted with morning set up and check in.



Thanks also go to our sponsors, including our headlining sponsor, Eaton Apothecary, and Sun Life Financial, West Suburban Imaging Center, Realty Executives, Skelmir, LLC, The Skellig, Clockwork Design Group, Inc., and the John Hancock Long Term Care Insurance Community Service Program.

For more information about the Scavenger Hunt and to see pictures, please visit the events section at www.acceleratedcure.org.

The Not-So-Average Birthday Party of a Not-So-Average Boy

Sean Reardon (left) and Christopher Guiffrida



On March 19, 2005, Sean Reardon turned eight years old. He had a birthday party at a bowling alley, which to many people looked like any other child's

birthday party, but this one was a bit different. Instead of gifts, Sean asked his friends to bring checks made out to the Accelerated Cure Project.

Kim and Joe Reardon, Sean's parents, had encouraged Sean the year before to request money for a charity instead of gifts. Sean did so with some reluctance, giving the money to an organization that helped abused children. He found that he got a good feeling from this and chose to do it again. This year, he

decided to help his friend Christopher's mother Sharon, who has MS, by supporting an organization that was working to cure her.

Kim and Joe asked Sharon what organization she wanted the money to support. She immediately chose the Accelerated Cure Project, saying, according to Kim, that it "was most on track towards working for a cure."

Sean feels good about his birthday gift and being able to help Sharon personally. With her recent flare-ups, Sharon has had difficulty going out, but she made a point to come to Sean's birthday party. She gave him a big hug, which brought an enormous smile to his face. We thank Sean for his selflessness, and for the generous people whose birthday contributions will help Sharon and everyone else with MS.

Accelerated Cure Project T-Shirt Pictures

Want a new Accelerated Cure Project t-shirt?

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



Tom, Anne, Emily, Mike, Nick and Carolyn Carey in Hopkinton at the start of the Boston Marathon



Melissa, Hollie, Julie and Art in Miami, after the American Academy of Neurology Annual Meeting

VOLUNTEERS

Our volunteers are a precious resource! These generous folks have been giving their time to Accelerated Cure Project in recent months:

VOLUNTEER STAFF

Susan Mellor -
Administrative Assistant

ADMINISTRATIVE WORK

Brian Mellor
Russell Lieberman

BOSTON MARATHON FUND RAISERS

Mark Aher
Anne Carey
Mary Carmichael
Mary Chaplin
Kelly Corrigan
John Gannon
Greg Higgins
Jacqui McCoy
Asha Mellor
Brian Mellor
Debbie Mellor
Krista Milne
Jess Pawlowski
Angela Robinson
Carol Rose
Lisa Sargeant
Norma Shamah
Sally Wiseman

CUTS TO CURE MS

Janelle Hamilton
Dean Claude

FITSENSE FUNDRAISING

Ashley Brody
Asha Mellor

FUNDRAISING

Tanya Africa
Maria Grace Curcio
Charlie Namias
Patricia Phelps

GOLF TOURNAMENT

Jayne Casey
Jacqui McCoy

LOW COUNTY MS TOUR 2005

Terri Bleam
Linda Socie

MARKETING

Mary Emsheimer
Randy Shipp
Laura Wooster

NEW YORK CURE PROJECT KICK-OFF PARTY

Philip Luongo
Jennifer Paretta
Stacey Schwartz

OPERATION MISSING LINK

Debbie Mellor
Katherine Mosley
Lily Towers

The African American Multiple Sclerosis Genetics Project at UCSF

By Jorge Oksenberg

In this issue of our newsletter, we are honored to present an article written by our scientific advisor, Dr. Jorge Oksenberg, about his efforts to find genes that influence the risk of MS. He and his group are making important discoveries about how MS develops, and in this article he describes how gene sequences carried by African-Americans can be used to search for the causes of MS.

The Multiple Sclerosis Genetics Susceptibility Project at the University of California, San Francisco is a multi-center research study dedicated to finding the underlying genetic cause of MS. The gene variants associated with MS are not themselves abnormal. In fact, some of them may be advantageous to have. But in some combinations, these normal genes play an important role in determining who is at risk for developing MS, how the disease progresses, and how someone responds to therapy.

We believe that knowledge of the genetic events that lead to MS will open opportunities for developing new therapies and possibly a cure.

MS is a disease known to affect African Americans, but the problem of MS in this community has not been adequately addressed because members of this group are thought to develop the disease less frequently than Americans of European descent. The most recent studies estimate that African Americans have a 50% lower risk

of developing MS compared to individuals of primarily Northern European descent. This observation suggests that African ancestry, as defined by unique genetic sequences, may reduce susceptibility for MS. It occurred to us that analyzing the genes of African Americans might therefore provide us with new insights into the causes of MS, and so we established an effort to do this.

Before describing this project, I will give some background on what genes are and what they do. Every organism's genetic information is contained within the nucleus of its cells, encoded in *deoxyribonucleic acid* (DNA). Human DNA contains approximately 3 billion building blocks called *nucleotides*, organized into 23 long strands called *chromosomes*. Located throughout the 23 chromosomes are 30,000 to 35,000 genes, which are the most basic functional unit of heredity. Genes consist of an ordered sequence of a few thousand nucleotides that encode instructions for producing *proteins*, which are important components of the human body, providing structure, transport, and other critical functions. We all have two copies of each gene, inherited from our parents - each parent passed along one of each chromosome and thus one of each gene to us. Likewise, we in turn pass along one of each chromosome and gene to our children.

Although we know what genes are, how they are inherited, and often

what proteins they encode, we have much still to uncover about them. You may have heard of the Human Genome Project, the goal of which is to discover the order of all 3 billion nucleotides and to identify and characterize all of the genes contained in human DNA. To borrow President Bill Clinton's metaphor, the full genome, which is our complete genetic sequence, offers researchers the sequence of all the letters of the human book of life, a monumental resource despite our imperfect understanding of its overarching complexity.

Although more than 99.8% of the human genome is constant throughout the population, each person's copy of the human genome is unique and differs in sequence from any other copy in the population by roughly one in 1,250 nucleotides. A small proportion of this individual variation clusters within ethnic groups or within broad geographic regions. This is due to the genetic relatedness between the members of the group and the group's common ancestral history. Most of this variation is inconsequential, but some common variants influence individual characteristics such as physical appearance and susceptibility or resistance to disease. Therefore, knowledge of ancestry is important in biomedical research when studying diseases that behave differently in different ethnic groups.

In fact, the study of populations with unique clinical, demographic, and/or

historic characteristics has been shown to be extraordinarily informative in deciphering the genetics of cancer and other complex diseases, including MS. For instance, years of effort studying DNA specimens obtained from patients of Northern European descent found a broad chromosomal segment associated with disease susceptibility but failed to differentiate two neighboring genes, the HLA-DRB gene and the HLA-DQB gene. In a recent publication of *The American Journal of Human Genetics*, we showed that the unique information embedded in the African American MS genetic sequence allowed for the identification of the specific disease gene, the HLA-DRB gene.

As indicated before, the prevalence of MS in African Americans is lower than in European Americans. However, the disease course may be more severe in some African American individuals and the response to MS medications may also be different. We documented some of these characteristics in a publication this year in the journal *Neurology* and proposed that genetic variants may comprise the underlying cause of rapid progression in MS.

Finally, in collaboration with colleagues at Harvard University, we have also been studying MS in African Americans in a new and exciting project to specifically search for the genetic variants that explain the difference in risk between Africans and Europeans. The study, called "admixture mapping," is the first of its kind in the United States and works by searching through participants' genetic material for sections where they have an unusually high proportion of European or African ancestry compared with the average.

Admixture mapping is based on our knowledge that on average 80% of the ancestry of African Americans is West African and about 20% is European. We hypothesize that for chromosomal regions with genes that affect peoples' risk for MS, however, the proportions should be different. Here, African Americans who have MS will have a

higher-than-average proportion of African or European ancestry, depending on which population has a higher risk for disease at the genetic level. We have already had some exciting successes with admixture mapping and just recently identified a region on chromosome 1 where there is a significantly higher proportion of European ancestry compared to the average. We are preparing these results for publication, and following up should identify the exact gene responsible.

We have so far studied about 600 African Americans with MS by admixture mapping, which we believe to be about 6% of all African Americans in the United States suffering from MS. However, we need to study more than 2,000 African Americans with MS, about 20% of all those in the country with this disease, to take full advantage of the power of this approach. With more than 2,000 samples, we hope to find several of the genes responsible for the specific types of MS more common in African Americans.

To confirm this important preliminary data and accelerate discovery, blood samples from a large number of African American MS patients and their family members are needed. With support from the National MS Society, the National Institutes of Health, and the Montel Williams and Nancy Davis Foundations, and in collaboration with important MS

(continued on page 6)

SCAVENGER HUNT TO CURE MS

Stephen Bell
Larry Cheetham
Nancy Costello
Susan Gilmore
Kathy Klingler
Anna Lipinski
Paul McCuen
Nancy Medeiros
Debbie Mellor
William Meyer
Kingsley Osei-Mensah
Greg Polite
Jane Shapiro
Catharine Sheehan
Stephanie Sisto
Amanda Song
Sherri Taylor
Lily Towers

SING TO CURE MS

Marion Leeds Carroll
David Goldhirsch
Sue Halliday
Ruth Seidman
Rebecca Enright

OTHER

Marcella Cross – Million Dollar Cue Project
Martha Garrett – Book Reviews
Kemp Jaycox – Cincinnati Expansion Team
Dave Kaffine – Donor Database
Rob Lester – MRI Economics Paper
Debbie Mellor – Dine to Cure MS
William Meyer – PR
Peter Schmidt – Volunteer Intro Document
Jen Tobin – Neuroanatomy Paper

CONTRIBUTED GOODS AND SERVICES

Clockwork Design Group, Inc.
Clock Tower Law Group
John Hancock LTC
Kirkwood Printing
Mail Perfect, Inc.
Torraspapel

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!

DONOR PROFILE

Mike and Lori Yashko



Mike Yashko became involved with the Accelerated Cure Project after his wife Lori was diagnosed with MS in May 2002. According to Mike, he and Lori were "shocked" to discover that, after 150 years of research, the cause of MS was still unknown. While Lori is doing well now, they are not content to simply stand by and hope for the best. "What seemed like common sense to us, discovering the cause of MS as the most direct route to finding a cure, was not the focus of the existing research," Mike said recently. After making a financial contribution to the Accelerated Cure Project in 2003, Mike and Lori decided they wanted to do more. They established the Yashko Family Fund to support our efforts, and with the generous support of family and friends have engaged in a very successful fundraising effort. Mike, although busy as a practicing attorney with the regional law firm, Roetzel & Andress, also finds time to serve on the Accelerated Cure Project's Board of Directors. We appreciate Mike and Lori's support!

The African American Multiple Sclerosis Genetics Project at UCSF

(continued from page 5)

clinical centers throughout the country, we have launched a large and ambitious genetic study of African Americans diagnosed with MS. If you are African American and if you or a family member have been diagnosed with MS, we invite you to join this landmark research project. Participation will include completing a family information form and donating a blood sample.

With a few exceptions, all of us in the US are relatively new to this land, some as recent as one generation ago, others as far as six generations ago, but more often we are second or third generation in this country. We bring with us the gene diversity that is characteristic of our ancestors and we mix. This fusion creates, in effect, a naturally occurring experiment whereby groups with slightly different gene pools live in a similar environment but have distinctly different disease risks. This unique situation provides a promising opportunity for comparative genetic studies that may reveal the genetic components involved in MS. We are hopeful that a greater understanding of the experience and genetics of African Americans will bring us closer to finding new treatments for patients of all ethnicities afflicted with MS.

If you are interested in participating in this study, please contact the UCSF Multiple Sclerosis Genetics Project at: 1 (866) 674-3637 box #1 or email msdb@itsa.ucsf.edu.

Frequently asked questions by prospective study participants

Q: Will my participation in clinical trials make me ineligible for the study?

A: No. Our study focuses on family history and genetics; therefore your participation in drug trials and even the medication you take are not disqualifying factors.

Q: Will my participation in the Accelerated Cure Project's sample repository make me ineligible?

A: No. You can participate in both studies.

Q: How do you collect my blood sample?

A: We have two methods to collect blood samples from individuals in the 50 US States: a) Portamedics, a national phlebotomy, service will set up a time to come to your house and collect the blood sample, or, b) a kit with all the materials needed to get your blood drawn locally at your clinic will be sent to your home. In both cases the blood sample will be delivered by courier to our laboratory in San Francisco the next day. In either case, we will not proceed with collection before we receive your signed Consent Form in which we explain in detail the study and procedures.

Q: Will I receive results from my blood test?

A: No. This is a population research study and not a clinical test. Individual results are not available because they are not helpful for the donor of the blood sample.

Q: How much will this cost?

A: There will be no expenses to you or any of the participants for being in this study.

Q: Will my privacy be compromised?

A: At all times, records and other information you share with the investigators will be handled in a strictly confidential manner. This research project is regulated and reviewed once a year by an Institutional Review Board, which was established to protect the rights of study participants.

Q: Why is the participation of relatives and/or friends necessary?

A: Our strategy for fueling gene discovery in MS relies on the meticulous scanning of the entire genome of patients compared to their relatives as well as to unrelated controls in order to identify the genetic differences linked to the disease. However, if your relatives or friends are not able to participate, you remain eligible for this study.

Q: I'm not African-American, can I still participate?

A: Yes. The goal of our project is to learn as much as possible about MS through genetic research. Please help us achieve our common goal. If you have been diagnosed with MS, we invite you to join this effort. This is one of the largest studies of this kind in the world, and every family counts. For additional information and enrollment criteria, please visit our web site at www.ucsf.edu/msdb/pr_participate, or contact us at the email address or phone number listed above.

EMPLOYEE PROFILE

Sarah Nels



Name/Nickname:

Sarah Nels

Occupation:

Events Manager

**Reason for joining
Accelerated Cure**

Project: I knew I would never be bored.

Last Job/Occupation: Marketing for a home health agency in Newton, MA

Current Residence: Somerville, MA

Hometown: Lafayette, NY

Ideal vacation spot:

I have two. In the winter, Miami, Florida. In the summer, Little Compton, Rhode Island

Most favorite thing:

The Sunday morning ritual of coffee, muffins, and the *New York Times*

Least favorite thing: Snow shoveling

Starfish Inspire Expansion Team from South Carolina

On May 7, visitors to the 2005 Bluffton Village Festival in South Carolina were given the opportunity to learn about and support the Accelerated Cure Project through the efforts of the Low County MS Cure, which hosted a table and sold handmade jewelry to raise money and awareness for our efforts.

Led by Terri Bleam and Linda Socie, the group has organized itself to promote the work of the Accelerated Cure Project. Terri, a jeweler by trade, created a special line of starfish crystal prisms, pendants, and ankle bracelets to represent MS and our efforts to cure it.

According to the group, "The MS Make a Difference Starfish prism appears to change color when it reflects the light, symbolizing the unpredictable, life-altering effects MS has on people's lives. The starfish itself is a symbol to our group, The Low County MS Cure,

of the difference the Accelerated Cure Project is making by researching the causes of MS as the first step in curing it." They chose the starfish as their symbol after hearing this inspiring tale:

Make A Difference

There was a young man walking down a deserted beach just before dawn. In the distance he saw a frail old man.

As he approached the old man, he saw him picking up stranded starfish and throwing them back into the sea.

The young man gazed in wonder as the old man again and again threw the small starfish from the sand to the water.

He asked, "Old man, why do you spend so much energy doing what seems to be a waste of time."

The old man explained that the stranded starfish would die if left in the morning sun.

"But there must be thousands of beaches and millions of starfish!" exclaimed the young man. "How can you make any difference?"

The old man looked at the small starfish in his hand and as he threw it to the safety of the sea, he said, "It makes a difference to this one!"

– Author unknown

To find out more about the Low County MS Cure project and their starfish jewelry contact Terri Bleam at 843-301-9011, terri@candybaubles.com.

Calendar of Upcoming Events

We hope you can join us for these events! For more information, go to www.acceleratedcure.org.

- **September 26:** Pull out the clubs and get ready for a day of fun at the **Fourth Annual Tee-Off to Cure MS** golf tournament at the Charter Oak Country Club in Hudson, MA.
- **October 29:** The **Fifth Annual Accelerated Cure Party** will be held at the MIT Faculty Club in Cambridge, MA, featuring a silent auction, guest speakers, and live entertainment.
- **November 6:** Treat yourself to a haircut, manicure, or other spa service at the third annual **Cuts to Cure MS** held in Norfolk, VA.

Boston Cure Project T-Shirt Pictures



Fran LaSalle, James Rose and Charlie Rose in Framingham at the Boston Marathon
Photo by Peter Rose



Lauren Milne in Newton after the Boston Marathon where she helped to cheer on runners



Mr. Bones O'Shea sporting a snazzy doggy t-shirt
Photo by Anthony O'Shea



Nonprofit Org
US Postage
PAID
Permit #4
Rutland, VT 05701
Prsrt Std

300 Fifth Ave.
Waltham, MA 02451

Tel: 781-487-0008
Fax: 781-487-0009

www.acceleratedcure.org
newsletter@acceleratedcure.org

Have you moved?
Changed your email
address? Let us know!
Send changes in
contact information to
newsletter@acceleratedcure.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 ACCELERATED CURE PROJECT:

By Check: make checks payable to Accelerated Cure Project and mail to:

Accelerated Cure Project
300 Fifth Avenue
Waltham, MA 02451

By Credit Card: On www.acceleratedcure.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.acceleratedcure.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@acceleratedcure.org.

Want an Accelerated 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, 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@acceleratedcure.org

Subscribe Now to Our Newsletter: Call 781-487-0008, email newsletter@acceleratedcure.org or go to www.acceleratedcure.org and click on "Sign Up." You may also unsubscribe using this contact information.

Subscribe Now to Our Electronic Mailing Lists:

Go to www.acceleratedcure.org. Click the "Sign Up" box at the top of the page.

MS NEWS WEB SITE: PRODUCED BY ACCELERATED 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.acceleratedcure.org.

Have you moved? Changed your email address? Let us know! Send changes in contact information to newsletter@acceleratedcure.org or call 781-487-0008!

ACCELERATED CURE PROJECT UPDATE VOL. 4 – SUMMER 2005

Newsletter Design & Layout contributed by:
Clockwork Design Group, Inc (www.cdgi.com)

Mailing House Services contributed by:
Rich Macaluso of Mail Perfect, Inc. (www.mailperfect.com)

Editor-in-Chief: Julie Morgenlender

Writers: Rachel Elias, Jorge Oksenberg, Mike Yashko

Photographers: Brian Del Vecchio, Kim Reardon,
Sharon Giuffrida

This newsletter is available online at www.acceleratedcure.org, in the "Downloads" section.