

Celebrating 10 years  
serving children  
with MS and  
advancing research  
to benefit all  
with MS



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## RESEARCH UPDATE - Stress and MS

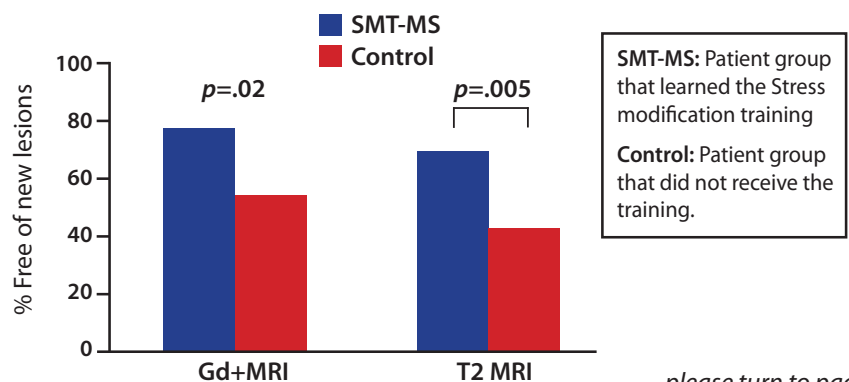
One question frequently asked of me is whether MS can be caused by stress. It's a difficult question to answer. First, to live is to face stress. So, while embracing life, avoiding stress is not an option. A number of studies have failed to show convincing links between stress and MS, however when people with MS apply stress reduction techniques, they can favorably modify their symptoms.

In a study of 150 people with MS, participants who underwent a technique known as Mindfulness experienced significant improvements in quality of life, fatigue, and depressed mood compared to those who received usual and standard medical care<sup>1</sup>. Mindfulness was taught in an 8-week program, requiring participants to attend 9 group meetings, including a weekend workshop, and also completed 40-minute homework assignments 5 days a week for 8 weeks. However, the benefits were not only present at the end of the treatment period, but persisted even months after the study was completed. In a more recent study, published this year, a similar stress reduction program demonstrated a significant decrease in the number of new MS lesions in the brain<sup>2</sup>. A total of 121 individuals with relapsing remitting MS were assigned by chance to either a stress reduction intervention or a wait list, meaning that they had the same evaluations at baseline and at the end of the treatment period (24 weeks) but did not receive the stress reduction training. At 24 weeks there was a dramatic reduction in the number of new brain lesions assessed by MRI among the treated relative to the controlled group. Figure 1 shows how the Stress Modification Trained group (SMT-MS) (blue) had fewer gadolinium-enhancing and T2 brain lesions than did the Controls (red)

It is remarkable that individuals can modify their disease by learning stress reduction techniques. These studies show that people have more power than they realize to alter the course of the disease. However, stress reduction techniques are not easy to learn and receiving the training can be expensive. Fortunately, Stony Brook has received funding to teach a stress reduction program to individuals with MS. The program is taught by professionals who have expertise in the area of mindfulness based stress reduction. Individuals interested in participating or learning more about this program should email us at [elayne.feld@stonybrookmedicine.edu](mailto:elayne.feld@stonybrookmedicine.edu) or call 631-444-7832.

Along with advances in what people with MS can do for themselves, there have been advances in the types of treatment options that health care providers can make available. At the time of this writing, another oral therapy has been approved by the Federal Drug Administration for use in MS, and two more agents are under review and likely to be approved late this year or next year. The most recent medication to receive

Percent of participants free of gadolinium-enhancing (Gd+) and T2 lesions by treatment group during 24-week treatment period



*please turn to page 2*

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## A New Beginning for our Pediatric MS Center



The year 2012 is a very exciting one for the newly named Lourie Center for Pediatric MS. This year marks the 10th anniversary of the Center, which was established in 2002 to address the unmet medical needs of children with MS. Earlier this year, Stony Brook University received a \$2.5 million gift from Robert and Lisa Lourie to help support the Center and imaging at Stony Brook Medicine. From that gift, \$1 million has been designated for the Center, which was subsequently named in honor of the Louries, and matched by the Simons Foundation Challenge Grant, providing a total impact of \$2 million.

Robert and Lisa Lourie were the honorees of this year's Harvest Sunset Dinner on November 15. The Lourie's passionate involvement is evident in everything they do — from their love of horses to learning about new scientific research and giving back to their local community.

The couple's route to success didn't follow a conventional path. Robert Lourie dropped out of high school and went on to spend six years in the Navy, during which time he taught himself advanced mathematics and physics, took the SATs and, upon his discharge at the age of 23, entered MIT. He never imagined that he would eventually earn a PhD from MIT, become a tenured Associate Professor of Physics at University of Virginia or Head of Futures Research at Renaissance Technologies. He also never dreamed that he would one day be in a position to have a meaningful impact on medical research.

When Lisa Lourie began her career as a nurse in Boston—working in ICU/CCU and later with AIDS patients — she certainly didn't foresee a day when her philanthropic efforts could have the potential to facilitate a cure for multiple sclerosis.

"The Center — the first of its kind in the nation — is dedicated to caring for children and adolescents with MS and conducting research that leads to advances in diagnosis and treatment," says Kenneth Kaushansky, MD, Senior Vice President of Health Sciences and Dean, School of Medicine. "Its strong multidisciplinary team of experts in MS, pediatric neurology, nursing, psychiatry, and neuropsychology has served as the national model for five similar centers across the country."

"Robert and Lisa's incredible generosity will help Stony Brook Medicine advance our mission of excellence in so many ways, including both imaging and neurological disorders," says Dr. Kaushansky. The Lourie's gift will have a focus on pediatric multiple sclerosis. Dr. Kaushansky continues "Their gift will allow our faculty to delve into the origins and markers of this devastating disease, hopefully leading to better diagnoses and potentially, treatments."

Lourie Center Director Lauren Krupp, M.D., agrees. "This combination of a PET scanner and MRI in the same unit — which allows two different and complementary imaging methods to be simultaneously applied — presents an exceptional opportunity to expand our research by enabling us to examine the brain tissue at the level of individual cell types," says Dr. Krupp. "The unique advances made possible by the MRI/PET scanner could dramatically impact the path of future research in MS."

Dr. and Mrs. Lourie hope their investment in the Lourie Center for Pediatric MS inspires charitable behavior in others. Their ability to give back has become one of their greatest joys in life. "The feel-good part of it is when you can incorporate your natural interests into your charitable giving," notes Mrs. Lourie. "It's not just a pleasure, we both feel it's a responsibility," adds Dr. Lourie. "We've been extremely successful, and part of that success is enabling things that wouldn't otherwise happen. The pleasure comes from finding the right ways to give."

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## RESEARCH UPDATE - Stress and MS *(continued from page 1)*

FDA approval is teriflunomide, an oral agent which, in two large phase III trials, significantly reduced relapse rate and decreased lesions on a brain MRI. It is taken once a day and acts to reduce the number of proliferating lymphocytes that in MS cause damage to the central nervous system. Safety monitoring requires blood tests several times a year to check on liver function and complete blood cell count.

Also published this year were the positive results of two phase III clinical trials for the medication dimethyl fumarate. In both studies, there was a clear reduction in relapse rate and brain lesions and in one of the two trials disability was lessened in the treated relative to the control group. These results are extremely encouraging and the future beyond these medications is equally exciting. There are over 125 different compounds under development for the treatment of MS.

Stony Brook took an active role in the advances occurring in MS therapy and clinical care. At theECTRIMS conference (the largest international meeting on MS) physicians at the MS

Comprehensive Care Center and the Lourie Center for Pediatric MS presented data on how to quickly and efficiently screen individuals with MS with respect to cognitive function, and also presented data on how well children with MS tolerate the disease modifying therapy interferon beta 1a SQ. Findings were presented on how children from the USA compare clinically to children with MS from other countries who are also on this therapy. Another presentation concerned the safety of stem cell therapy as a potential MS treatment. Exciting results from theECTRIMS conference (Oct. 10–13) will be available to individuals participating in a conference call, scheduled for November 26 at 7 pm, in which Dr. Krupp will be sharing the exciting research presented at the meeting.

The challenge of MS continues for patients, families, and health care workers. However, each day we move forward in advancing the quality of life for people affected by the disease, improve therapies, and come closer to stopping the disease entirely.

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<sup>1</sup>Grossman P, Kappos L, Gensicke H, D'Souza M, Mohr DC, Penner IK, Steiner C. *MS quality of life, depression, and fatigue improve after mindfulness training: a randomized trial.* Neurology. 2010 Sep 28;75(13):1141-9.

<sup>2</sup>Mohr DC, Lovera J, Brown T, Cohen B, Neylan T, Henry R, Siddique J, Jin L, Daikh D, Pelletier D. *A randomized trial of stress management for the prevention of new brain lesions in MS.* Neurology. 2012 Jul 31;79(5):412-9. Epub 2012 Jul 11.

# HAPPENINGS

## Teen Adventure Camp 2012

Teen Adventure Camp 2012 was a resounding success and we give thanks to the staff, volunteers, mentors, campers, families and generous donors who made it possible.

In July, 41 teens with MS travelled from all corners of the US to spend a week in the beautiful woods of Rhode Island, learning and growing, developing friendships and challenging themselves with outdoor adventures.

This year we were able to expand our mentor program to include a full day of counselor training. During this time, our mentors—young adults with MS who had attended our camp



program in the past—developed the role of peer mentor and participated in program planning for the upcoming week. Mentors and staff all shared time together, catching up on current news and strengthening the bonds of friendship that have been forged over the years.

In addition to the educational component of the camp, the most compelling part of our Teen Adventure Program is the bond established between campers which becomes a source of strength and comfort once kids have returned home. As the new campers arrived on site, the mentors welcomed them with the message that they were about to create a peer support group that would continue long after camp ended. As one mentor introduced another mentor to the group, he explained, "This is my best friend in the world, someone who knows me better than anyone else, someone that I can talk to when I am having a bad day, someone who understands me completely....and who I have only been with for a total of 4 weeks".

The friendships and support endure, as the teens stay connected once back home. Their thoughts are already turning to summer 2013 and the fun that will be shared as we all celebrate the upcoming 10th anniversary of the Teen Adventure Camp.



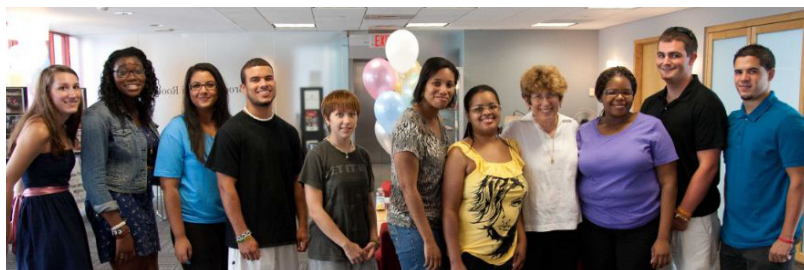
## Patient Anniversary Celebration

On Sunday August 5, 2012, the Lourie Center for Pediatric Multiple Sclerosis (MS) held a patient reunion in the Brooks Alumni Room at the Wang Center on the Stony Brook University campus. The Center has much to celebrate this year, as 2012 marks ten years since the Center was founded by Dr. Lauren Krupp.

The event brought together a mix of familiar and new patients along with their families. The Center's first-ever patients were also there, proudly both continue to be followed by Dr. Krupp.

The day offered many opportunities for kids to bond with one another, fulfilling another of the Center's goals, which is increased connectivity and social support within the young MS community. Many attendees already knew each other from the Teen Adventure Program (TAP) that is run by the Lourie Center every summer. Now in its 8th year, the TAP is the only MS program of its kind anywhere in the world. Designed to teach young patients about their disease and ways to live a healthy life, camp offers tools to build a positive self-image while developing confidence and life-long friendships.

It was a heart-warming event, filled with families and kids happy to be with one another. "We should do this every year" was said many times throughout the afternoon.



## The Summer Soiréé by Day June 2012



*The 2012 Summer Soiréé Committee*



*Merry & Richard Slone*

## Celebrate 10 Years of Pediatric MS Care and Research

Make your tax-deductible donation to the Lourie Center for Pediatric MS **online** by simply going to **Stonybrook.edu/pediatricmsgiving**

We offer memorial and honor donations. Please contact us at 631-444-1454 or email [dominique.stanley@stonybrook.edu](mailto:dominique.stanley@stonybrook.edu)



## SPECIAL THANKS

The Lourie Center for Pediatric MS would like to thank all of its donors, supporters and volunteers. Your involvement makes it all possible.

A very special thanks to Lisa & Robert Lourie, Merry & Richard Slone and the Slomo and Cindy Silvan Foundation for their research and clinical support. A very special thanks to Cynthia Marks, the William Marx Foundation, the Winston Foundation, and Michael & Debra Brooks for their generous support of the Teen Adventure Program.

## UPCOMING EVENTS

### **Monday, November 26, 2012 – MS Teleconference**

To register email [elayne.feld@stonybrook.edu](mailto:elayne.feld@stonybrook.edu) or call 631-444-7832

### **Thursday, December 13, 2012 – Pediatric MS Teleconference**

To register email [elayne.feld@stonybrook.edu](mailto:elayne.feld@stonybrook.edu) or call 631-444-7832

### **January 2013 (date TBD) – Winter Camp, NYC**

Email [maria.milazzo@stonybrook.edu](mailto:maria.milazzo@stonybrook.edu) for more information

### **Saturday, March 23, 2013 – New York Islanders vs. Montreal Canadiens fundraiser game.**

Email [dominique.stanley@stonybrook.edu](mailto:dominique.stanley@stonybrook.edu) or call 631-444-1454 for more information

## About the MS Centers

There are two MS centers located within Stony Brook Medicine, both designated Centers of Excellence by the National Multiple Sclerosis Society.

The MS Comprehensive Care Center is headed by two internationally recognized experts in MS, Drs. Patricia K. Coyle and Lauren B. Krupp, providing expertise and the latest cutting edge treatment and information to adults with MS.

The Lourie Center for Pediatric MS, founded and directed by Dr. Lauren Krupp, is committed to improving the lives of children with MS and advancing a research program that will benefit all people with MS.

MS Comprehensive Care Center 631-444-MSCC (6722)  
Lourie Center for Pediatric MS 631-444-7802  
Mail: Dept. of Neurology, HSC L12, Room 020, Stony Brook, NY 11794-8121

*Would you like to raise money for children with MS? Hold a bake sale, organize a walk, hold a bowling party or get creative and come up with your own idea. We can help YOU make a difference – Call 631-444-1454 to learn how!*

MS Comprehensive Care Center/  
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Stony Brook Medicine  
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