Even while lying in bed unable to move her legs, Meredith McClurg never considered the fact that she might never be able to walk again. It was this perseverance that helped her to recover from a devastating bout of Transverse Myelitis (TM). TM is a rare inflammatory disorder of the spinal cord which affects between 1 and 8 people per million per year. Shoveling snow on a typical Maine morning just after the New Year in 2003, Meredith never considered she would be one of the few people stricken with this disease.

Meredith was an active young adult who enjoyed running and playing soccer, but that January morning she recalls telling herself to “slow down” to avoid overexerting herself while hauling the heavy snow. Feeling a sudden pain under her rib, she decided to take a break and lay down for a bit, but woke up with an upset stomach. As the symptoms progressed over a few hours, she experienced intense pain and found herself unable to get down the stairs. Panic immediately set in as she watched her dad become more and more nervous about her declining condition.

Meredith was rushed to the hospital and arrived completely unable to move her legs. After undergoing a battery of tests over three days for Lyme, HIV, etc., she was ultimately diagnosed with TM. (**continued on page 4**)

On the morning of April 13th, 2008, people from all over Baltimore City and County arrived at Towson University to participate in the National Multiple Sclerosis Society’s (NMSS) annual MS Walk. Teams comprised of people of all ages, many being co-workers, family members, friends, and neighbors. Those who were walking for a family member or friend with MS created team web pages to raise awareness about their loved one’s experiences with the disease and to elicit more widespread support. All walkers were asked to make a pledge or donation to benefit the 6,500 people with MS in Maryland. The Johns Hopkins MS Center and Project RESTORE participated with our friends, families and patients. The funds raised by the event will go toward supporting multiple sclerosis research.
Meyerstown – In a few years, doctors may be able to stop – perhaps even cure – serious eye disorders, such as macular degeneration. Dr. Colin J. Barnstable offered those with severe eye diseases some hope as he talked about promising research using stem cells to restore vision.

Barnstable was the keynote speaker at the Greater Lebanon Valley Lions Club dinner/lecture at the Lantern Lodge last night. He is professor and chairman of neural and behavioral sciences, and director of Penn State Hershey College of Medicine’s Neuroscience Research Institute in Derry Township.

Barnstable’s group of researchers was the first to show that stem cells of the retinal pigment epithelium – pigmented layer of cells behind the retina – could be converted into retinal tissue. This research holds the potential of stopping or curing some eye diseases, including glaucoma. Millions of people each year lose their sight as a result of macular degeneration, diabetic retinopathy and glaucoma. Barnstable said HMC researchers are trying to define the causes of major blinding diseases as well as finding ways to slow down or stop the cells in the retina from dying.

“Because the nerve cells are the things in the eyes that are dying (in these disease), we are particularly interested in a series of molecules that can actually stop cells from dying,” he said.

Researchers have discovered a small protein – called PEDF – that is very powerful in stopping retinal cells from dying, he explained. But that will help patients only if doctors can catch the disease early. Stem cells hold more promise for those who already have lost cells.

“I think the hope there is to replace them using stem cells as a source of new tissue,” he said. Barnstable said HMC does some stem-cell research. For now the research is limited to a controlled environment in the laboratory, he said. “We haven’t found a way within a patient to actually stimulate them (stem cells) to do something useful,” he explained. “Our work is not far enough along to transfer it to humans.”

Dr. Douglas Kerr, associate professor of neurology, molecular microbiology and immunology and director of the Johns Hopkins Transverse Myelitis Center, said the most powerful and immediate benefit of embryonic stem cells will be to study disease rather than treat it. “I think the concept of transplanting embryonic stem cells into patients still has a long way to go. They are very powerful, but it’s hard to know how to control them,” said Kerr, who also spoke at the meeting.

Dr. Mark Maria of Fava and Marian Eye Associates, Lebanon, who introduced his colleagues at the lecture, said the most frustrating aspect of practicing medicine today is not having the tools to help people. “As our population ages, the number of patients we end up taking care with serious eye problems increases,” he said. “Yet we lack many tools to cure those problems.”

Stem-cell research “holds the promise of a cure for those problems,” he added. That’s the exciting thing about research.” Article courtesy of Lebanon Daily News, written by Chris Sholly

A Step in the Right Direction (continued)

Teams were certainly enthusiastic about the walk, arriving in brightly colored team t-shirts for the early morning 5K. Not a cloud in the sky, walkers could not have asked for better weather. The event was a success, with the top Maryland team raising almost $40,000. The total raised in the 2008 Campaign which hosts walks all across the state of MD is $1,195,754.30. Thanks to the spirit and dedication of the Maryland walkers, researchers may get a few steps closer to finding a cure for this chronic disease. For more information about next year’s walk go to:

www.nationalmssociety.org
HiCy Drug Regimen Reverses MS Symptoms In Selected Patients

A short-term, very-high dose regimen of the immune-suppressing drug cyclophosphamide seems to slow progression of multiple sclerosis (MS) in most of a small group of patients studied and may even restore neurological function lost to the disease, Johns Hopkins researchers report. The findings in nine people, most of whom had failed all other treatments, suggest new ways to treat a disease that tends to progress relentlessly.

“We didn’t expect such a dramatic return of function,” says Douglas Kerr, M.D., Ph.D, associate professor of neurology at the Johns Hopkins University School of Medicine. “Although we’re very early in the game, we think this approach could be the linchpin of a significant advance for MS treatment.”

Researchers have used the so called HiCy treatments with some success at Johns Hopkins for a variety of other immune system disorders, including aplastic anemia, lupus and myasthenia gravis.

Cyclophosphamide kills immune-system cells but spares the bone marrow stem cells that make them. The usual method of delivering it in pulsed, small doses, however, can cause the drug to build up to toxic concentrations in patients’ bodies, causing a variety of side effects, including a greatly increased risk of infection.

Seeking an alternative way to use the drug, Kerr and his colleagues reasoned that HiCy might clear out the majority of a patient’s immune system in one fell swoop, then allow it to “reboot,” giving nerve cells a fresh start and an opportunity to repair themselves. In the current study, nine MS patients got a total single infusion of 200 milligrams per kilogram of cyclophosphamide intravenously over four days, a dose several times higher than that given in pulsed regimens but significantly lower than the total amount usually given patients over time.

Before treatment, Kerr says, the study participants were “the worst of the worst” among MS patients. Eight of the nine patients had failed conventional MS treatments, and several of them were wheelchair-bound.

Reporting in the June 9 Archives of Neurology, the Johns Hopkins team said the disease appeared to reverse course for seven of the nine patients over two years following treatments. Overall, the patients, men and women ranging in age from 20 to 47 at the beginning of the study, experienced a 40 percent reduction in scores of a standard test that measures disability. They also had an overall 87 percent improvement in scores on a composite test that measures physical and mental function.

MS, which affects approximately 400,000 people - predominantly women - in the United States, is believed to occur when the body’s immune system attacks the insulating sheath that coats nerve cells, causing it to degenerate. Consequently, electrical signals that the cells use to communicate with the rest of the body become progressively weaker, leading to symptoms that include numbness, tingling, cognitive problems and sometimes paralysis.

Researchers have identified four different subtypes of MS, and each is thought to be caused by a different autoimmune process. As a result, developing a treatment that effectively targets all types of MS has been challenging, says Kerr.

Kerr cautions that the “reboot” phenomenon didn’t work in all the patients. Two years after treatment, MRI images showed that the disease had reactivated in about half the study participants, suggesting that their renewed ability may not be permanent.

Kerr’s colleague Adam Kaplin, M.D., Ph.D., assistant professor of psychiatry and neurology at the Johns Hopkins School of Medicine, is leading efforts to improve HiCy therapy with a blood test in development that could predict which patients would benefit the most from HiCy treatment. Also, since immune cells that regrow after HiCy treatment may contain the same defect that leads to MS, Kaplin and his colleagues are working on a way to regrow only healthy immune cells.

Originally Johns Hopkins Medicine Media Relations and Public Affairs Press Release
This period was much more scary for her parents than for her; they were facing the brunt of the uncertainty surrounding her condition while she was heavily medicated to alleviate the pain.

Meredith’s family took an active role in her care, researched her disease, and got in contact with Dr. Douglas Kerr, Director of the Johns Hopkins TM Center. Although she arrived at Hopkins barely able to wiggle her toes, the support of her family and Dr. Kerr pushed her through the roughest periods. Meredith was anxious to “be able to hop out of bed” but recalls that when Dr. Kerr smiled as she started to move her toes she felt secure and confident that she would recover. She reminisces, “He was so personal. He gave me his cell number. He had a huge heart, and I always looked forward to his visits.”

However, Meredith proclaimed that she wanted to get better for herself, not the doctors, and she rehabbed up to three times every day in order to regain function and strength. Some of her toughest moments came during the acute phase. Meredith was particularly frustrated by occupational therapy. She recounts, “Although the occupational therapist was incredibly sweet, I did not want help brushing my teeth or putting on socks. I wanted physical therapy. I wanted to be up walking.” She distinctly remembers the day when a nurse prompted her to take her first steps. Although initially unsure of her ability to walk, she walked out of the bathroom, into her hospital room, and into the hall. “It gave me hope,” says Meredith about these first steps towards recovery.

Meredith was discharged from the hospital at the end of January using a walker, and she completed an intense rehab program in June of that same year. She no longer needed to use a cane but still had a limp. Meredith liked the fact that she had no set recovery plan. She said the attitude of the therapists was “whatever you can do is awesome,” and that kept her motivated to keep pushing for more improvements.

This winter Meredith was able to ski one of the slopes in Maine. She has been doing Pilates and yoga to help with her leg strength. She can also run about 200 yards before experiencing stiffness. Although this inability to run for long distances might depress a former runner, Meredith says that when feeling stiff after running she can walk a bit and then pick up running again. This cycle gives Meredith hope that her running ability will continue to improve.

Meredith’s experience with TM has helped her “to learn to read her body.” Despite some lingering bladder problems, Meredith keeps a positive attitude: “These are small worries. I can ski. I can hike.” Meredith has even started dancing again. When asked about how her life has changed since TM she said, “Sometime I feel like I can have an accident at any time because I still have some balance problems. But, not too long ago my friends convinced me to go dancing. They said they would be there to catch me if I needed it.” Meredith attributes much of her recovery to the support of her family and friends, but in the end it is her own perseverance that has allowed her to get out of the bed and start dancing again.

Meredith atop Mt. Bachelor

Hopkins RESTORE Team is competing in the Cascade Lake triathlon in Hampstead, MD on May 31, 2009.

If you or a loved one would like to support our effort, please join our team!

For more information, please contact Edward Hammond at (410) 502-8626
Loving Tributes

Honorees are listed first in bold print followed by the names of those making gifts in their honor. This list reflects gifts made to RESTORE in honor of a loved one between February 1, 2008 and October 31, 2008. If you wish to remain anonymous or change the way we have listed your name, please contact Katie Kessenich at kkessen2@jhmi.edu. Thank you for your support!

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A copy of the current annual financial statement for Johns Hopkins is available by writing to: The Johns Hopkins Institutions 3400 N. Charles Street, 600 S. Wyman Park Building, Baltimore, MD 21218 or by phoning (410) 516-8046.

Additional Ways to Give
Symposium Success!

Our 3rd International Rare Neuroimmunologic Disorders Symposium sponsored by The Transverse Myelitis Association and The Johns Hopkins Project RESTORE was held from July 16-19, 2008 in Redmond, WA. Physicians, nurses, researchers, patients and their caregivers came together to learn, share, discuss and better understand these neuroimmunologic diseases including multiple sclerosis, transverse myelitis, neuromyelitis optica and acute disseminated encephalomyelitis (ADEM). More than 150 participated and we had patients from Ghana and Sri Lanka join us this year! Patients and family members volunteered in one of our largest research repository studies with the Accelerated Cure project (ACP). We collected blood samples and data from 39 study patients, a record number in one day! “We couldn’t have asked for a better turn out,” says Jana Goins, the Hopkins ACP study coordinator, “These samples paired with data are going to help us understand these diseases and put us closer to a cure.”

The three day symposium ended with a banquet where we honored Kyle and Patti Petty; and Dr. Peter Sim of the Victory Junction Gang Camp (VJGC) in Greensboro, NC. The camp opened their doors to our TM families in 2006 and have changed the lives of so many children with chronic illnesses. We honor their work and thank VJGC for partnering with us.

Director’s Column

Fall is here or is it winter already? Change seems to be the buzzword at RESTORE too! In July, I left my full time position in Neurology to become the Assistant Director at Johns Hopkins Medicine International. It has been a whirlwind 4 months for me. I have missed the research, the camaraderie, my colleagues and friends! I remain committed to RESTORE and will continue as a member of the Board. We are sincerely grateful to Edward Hammond who has stepped in as the interim Executive Director of Project RESTORE!

With mixed feelings, we share with you that Dr. Ben Greenberg will be moving to University of Texas South Western in Dallas. As heartbreaking as it is to see him go, we are excited for our patients and for research as he embarks on developing the 2nd Transverse Myelitis Center in the world. We are looking forward to much meaningful collaboration and making great strides in developing new therapies in MS and TM.

We will miss Ben’s infectious enthusiasm, his laughter, his sense of humor, his great ‘can-do’ spirit and above all Ben the consummate clinician. As all good things cannot go on forever, we wish Ben the best and look forward to hearing of phenomenal discoveries!

In this issue, we share with you the story of a beautiful, brave and resilient young woman Meredith McClurg. Diagnosed with TM in 2003, Meredith’s journey from paralysis to the top of Mt. Bachelor is one of perseverance and faith.

In June, we published our paper based on the results of a pilot study on the use of high dose cyclophosphamide (HiCy) in aggressive MS. The study shows much promise as we continue to investigate the results in a larger population. Dr. Robert Brodský and Dr. Richard Jones have pioneered this approach of “re-booting” the immune system using HiCy and more than 200 patients with diseases such as aplastic anemia, myasthenia gravis, lupus, multiple sclerosis have been on this therapy for their aggressive disease. It usually takes about 12 years from when an idea is thought of in a laboratory to an approved FDA drug. Since this drug has been in use for years now as a chemotherapeutic agent, we maybe much closer than 12 years! We have been encouraged by the results and are now expanding this study.

Project RESTORE traveled to Redmond, WA for our third bi-ennial International RNDS Symposium in July. The TMA hosted us and our heartfelt gratitude goes out to all, especially Paula Lazzerei, Megan Quigg and Carrie Trecker for making it happen!

As I write this column, I am sitting at the airport in Panama. Television screens are tuned to CNN and the local news channels are abuzz with stories of hope and resilience. Although we continue to struggle with our shaken economy, our commitment to medicine and scientific firsts continues. We are striving very hard everyday to better understand and treat these diseases and we thank you from the bottom of our hearts for your continued support. You give us hope and your faith means a lot to us as we move on to conquer new boundaries.

Sincerely,

Chitra Krishnan