

# LOOKING FORWARD

Fall/Winter 2011

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Dear Friends,

It seems like just yesterday when we wrote to you anticipating the longer days of summer, and now we are watching the leaves fall! We hope everyone had an enjoyable summer. Looking Forward is our publication for you, and allows us to introduce you to our team, keep you informed of exciting research projects, highlight clinical care, and most importantly, allows patients and family members to tell you their personal stories.

Probably our most exciting news is the addition of Assistant Professor Ellen Mowry, MD to the MS Center team. Ellen comes to us from the University of California, San Francisco and is the principal investigator on several exciting research projects; particularly in Vitamin D research. Ellen is an excellent clinician and brings with her tremendous enthusiasm and passion for comprehensive care. She is a wonderful addition to our team!

In this edition, we also highlight our Infusion Center. Staffed by expert nurses, Kristie Albright, Alpa Uchil and Amanda Augsberger, our infusion center provides IV treatments to approximately 200 patients every month.

On page 3 we feature one of our researchers, Emily Potter, Ph.D. It is the hope that her exciting research will one day translate into a treatment for MS that could promote myelin repair.

Lastly, we are very pleased to have an article penned by Gary Pinder, a current patient at the MS Center, which highlights his journey with Multiple Sclerosis since his diagnosis in 1995. It is truly an inspirational story of strength, perseverance and the power of family.

We hope that you enjoy this issue of Looking Forward. We welcome your comments and suggestions for future issues. We thank all of you for your continued support of our efforts to better understand and one day conquer the many immune mediated diseases that affect the central nervous system.

*Sincerely,  
Peter Calabresi  
Carlos Pardo*



## In this Issue:

- Letter from the Directors
- A Visit to the Johns Hopkins Infusion Center
- Research News: Promoting repair in Multiple Sclerosis and Transverse Myelitis
- My Diagnosis with MS: A Patient's Story
- New Faculty Spotlight: Ellen Mowry, M.D., M.C.R.

## A VISIT TO THE JOHNS HOPKINS INFUSION CENTER

KRISTIE ALBRIGHT, RN

ALPA UCHIL, RN

The Johns Hopkins Neurology Infusion Center is the home away from home for many of our patients dealing with Multiple Sclerosis (MS). MS is an inflammatory disease of the Central Nervous System. It is caused due to the inflammation and demyelination of nerve cells, which results in damage. As a result, there is poor conduction of electrical signals. This presents as cognitive, visual, motor and/or sensory events. MS lesions occur in different locations in the brain and/or spinal cord, and have different stages of severity. Therefore, the outward effects of the disease can be varied from person to person. Some examples of MS related symptoms are: fatigue, numbness, tingling, difficulty walking or keeping balance, optic neuritis, vision problems, and memory. MS is the most common disabling neurological disease of young adults.



**Left: Kristie Albright and Right: Alpa Uchil serve as full time RNs in the Johns Hopkins Infusion Center.**

The Infusion Center is located in the Johns Hopkins Out-Patient Center. Various treatments for MS and TM are administered in the Center including Natalizumab, Rituximab, methylprednisolone and first dose oral fingolimod. The highest percentage of patients, approximately 80% are seen in the Infusion Center for natalizumab infusions. Natalizumab (Tysabri) is an intravenous infusion therapy for relapsing-remitting types of MS (RRMS) given every 28 days. The Johns Hopkins Neurology Infusion Center is where patients with RRMS visit once a month for their treatment with natalizumab. Natalizumab is a monoclonal antibody that works by blocking the movement of inflammatory immune cells into the central nervous system.

The infusion center serves as a support group and resource center where patients share their ideas and information about MS and TM. The comfortable atmosphere promotes communication and valuable discussions among the patients. The Infusion Center is staffed by two MS specialist nurses. In addition, there is a physician on call at all times. The nurses, Kristie Albright and Alpa Uchil provide much needed emotional support to patients and also education about MS, new research and treatments. Their expert assessment skills are also vital to patient safety as well as ongoing disease management. Due to the monthly dosing regimen of Natalizumab, nurses and patients develop a strong therapeutic relationship built upon mutual goals and trust.



**Brian seated with Kristie and Alpa receiving treatment.**

One such patient is Brian. He was started on Natalizumab in January 2007, and has been coming to the infusion center every 28 days. In the last 4 years, Brian has noticed that his MS has not gotten worse, and that his symptoms have stabilized. While MS has no known cure yet, medication therapy is an effective way to stabilize disease progression. Brian also states that he stays active and works out regularly - in doing so, he stays fit both mentally and physically. Brian has formed friendships at the infusion center with other patients, along with professional relationships with the nurses and physicians.

For Brian, Natalizumab has worked very well. According to him, he should be the spokesperson for Natalizumab! The results have been very positive for Brian with a reduction in relapses and an overall improvement in his quality of life.

Brian is such positive influence in the Infusion Center as he is always in a good mood, always smiling, and striking up conversations with other patients. His positive attitude is infectious, giving a lift to other patients as well as the nurses!

While natalizumab is not for everyone, it has been very helpful to many patients and provided them with disease stabilization. In addition, the Infusion Center at Hopkins has become a social and support group of sorts for patients and their families. There is a positive as well as hopeful atmosphere in the Infusion Center making it a place of camaraderie and comfort for all.

# RESEARCH NEWS

## PROMOTING REPAIR IN MULTIPLE SCLEROSIS AND TRANSVERSE MYELITIS

EMILY POTTER, RESEARCH FELLOW

To effectively conduct the electrical signals that underlie our every thought and movement, nerves within our brain and spinal cord are insulated by layers of a fatty substance known as myelin that is generated by cells called oligodendrocytes. Multiple Sclerosis (MS) and Transverse Myelitis (TM) are immune-mediated diseases of the brain and spinal cord that result in loss of myelin and subsequent injury to the nerves. Patients with MS and TM can suffer devastating consequences including paralysis and loss of vision.

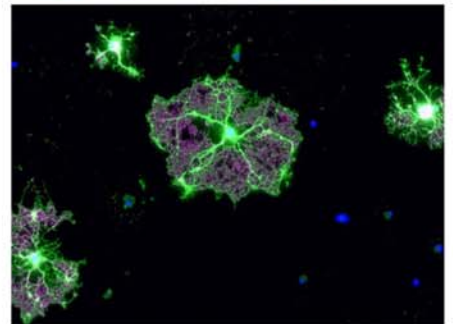
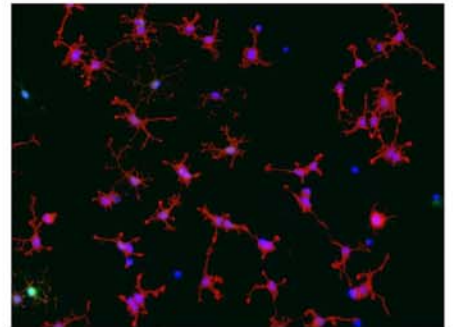
Prevalent through-out the brain and spinal cord are a population of cells known as oligodendrocyte progenitor cells (OPCs). In response to injury, such as occurs in TM and MS, these cells can mature into new myelin-producing cells and partially repair the damage. However, the repair process is sometimes stalled; OPCs reach the injury site, but fail to completely mature into new myelin-producing cells.

When I joined Peter Calabresi's laboratory in early 2008, our goals for my research were lofty but clear; develop a model system to assess the ability of candidate drugs to promote the generation of new myelin-producing cells. We made use of genetically designed mice to create a system whereby OPCs treated with a myelin-promoting drug, turn from red to green. Using this system, we found GC-1, a drug related to thyroid hormone, enhances the generation of new myelin-producing cells. It has been known for many years that thyroid hormones play a critical role in developmental myelination. Thyroid hormone itself would not be a suitable treatment for MS/TM patients since excessive levels can produce cardiac, mood and other undesirable side-effects. GC-1 has less potential for side-effects and therefore might hold therapeutic potential.

We have confirmed that GC-1 promotes myelin generation from both mouse and human-derived OPCs and are currently testing its ability to promote repair in a mouse model of MS.



Emily Potter, Research Fellow



Cells isolated from mice fluoresce red as OPCs (upper picture) but turn green when they mature into myelin-producing cells after treatment with the thyroid hormone related drug, GC-1 (lower picture).

FROM DEVELOPMENT:  
FUNDRAISING  
ACCOMPLISHMENTS!

This fiscal year, 7/1/10 to 6/30/11, we have received \$701,138 in gifts and pledges. This number includes gifts to the division, Project RESTORE and individual faculty within the division. Most if not all of it supports MS, TM and related neurology research, care, and education.

# THANK YOU!

# MY DIAGNOSIS WITH MS: A PATIENT'S STORY

GARY PINDER

Its the summer of 1995. Recently married, we had just moved to Chicago to start graduate school. I am at home on my 30th birthday studying for a test, when I noticed a disturbance in my vision which within a couple of days developed into double vision. An Ophthalmologist ordered an MRI. A couple of days later I received the news. "I need to refer you to a Neurologist" she said..."the MRI findings are consistent with Multiple Sclerosis(MS)". Totally relieved that it wasn't the brain tumor I had feared, but....Neurologist? Multiple what?

It took 5 years of grieving the life I had lived until I fully processed the idea that I had been diagnosed with this catastrophic illness. Those 5 years resulted in a new identity, new objectives for life, a new sense of what it was to be me, to be us with my darling Lisa. Throughout I clung to and sought out that most important word in the lexicon of an MS sufferer. Hope. Hope that something I came across - a medication, a vitamin, a diet, a program, exercise, anything - will overcome the odds and hold at bay the incurable illness that the lottery of life had awarded me.

I have just spent the past 3 years receiving monthly infusions of Tysabri. Starting on this drug, with its attendant risks, was not an easy decision. But, the other available DMTs had either not worked for me - or had worked successfully for many years but for some reason stopped working! I was concerned that I was entering a more progressive phase of this disease. I judged that the probability of significant disability without a DMT to be much greater than the probability of the side effects that Tysabri can cause. So, Tysabri entered my life. It achieved the intended goal of halting relapses, making my condition stable once again. I got to meet many inspiring MS patients in the Neurology Infusion Center.



**Gary and his family in Nepal**

Today, while I am aware of the physical impacts of many relapses on my body, sixteen years post diagnosis I know that I have been fortunate. For the majority of those 16 years I have not had to bear the extreme physical distresses that many MS patients cope with on a daily basis. Why? I offer the following reasons. I was in the first generation of MS patients to be on Disease Modifying Therapy (DMT) very soon after diagnosis. I have been able to take advantage of the expertise, research programs, dedication and care of the staff of both the Johns Hopkins MS Center and the Kennedy Krieger Institute. I was and remain physically active. And my family (wife Lisa, Brianna age 14 and Kyle age 13) have been a constant source of peace, love, support and motivation to stay healthy. And I have been lucky! Owing to all of this, in April 2011 I was able to hike to Everest Base Camp in Nepal with my family. Something I would never have been motivated to do without MS in my life...how cool is that?

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If you would like to receive information on the following efforts, please check those that apply and provide your contact information at the bottom of the form (email preferred). All selections are completely optional. Together we can improve care today and develop better treatments for tomorrow.

- General information and activities involving the Multiple Sclerosis and Transverse Myelitis Centers, including newsletters, periodic announcements, group educational sessions, support groups, and outreach efforts.
- Current research studies and inclusion in our Recruitment Registry, which will allow us to contact you and discuss future research opportunities, including clinical trials for which you may be eligible. Having your information in the Registry does not obligate you to participate in any study, and participation in all studies is always optional.
- Philanthropic efforts to raise awareness and funds to support Multiple Sclerosis and Transverse Myelitis care, outreach efforts, research, and treatments.

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Email us for more information at [projectrestore@jhmi.edu](mailto:projectrestore@jhmi.edu)

**Mail to: The Johns Hopkins School of Medicine  
Department of Neurology  
600 N. Wolfe St., Pathology 509 Baltimore, MD 21287**

# NEW FACULTY SPOTLIGHT

INTERVIEW WITH ELLEN MOWRY, M.D., M.C.R.  
ASSISTANT PROFESSOR, DIVISION OF NEUROIMMUNOLOGY

INTERVIEW CONDUCTED BY KATHY COSTELLO

**KC: What brought you here to Johns Hopkins?**

**EM:** I knew Johns Hopkins to be an exceptional environment for young researchers. The opportunities available here as well as the support and collaborative opportunities with colleagues have already been outstanding. I have also worked with Dr. Peter Calabresi in the past and knew him to be an excellent researcher. I feel privileged to have the opportunity to work at JHU in this esteemed and qualified department!



Ellen Mowry, M.D., M.C.R.

**KC: Thank you Ellen! Can you explain your educational background to us?**

**EM:** I became interested in multiple sclerosis prior to beginning college and first performed research in multiple sclerosis as an undergraduate biology major at Georgetown University in the laboratory of Dr. John Richert. After I obtained my M.D. at the University of Rochester, I completed a medicine internship and neurology residency at the University of Pennsylvania, where I evaluated visual dysfunction and quality of life in multiple sclerosis with Dr. Laura Balcer. In July of 2007, I joined the MS Clinic at the University of California, San Francisco (UCSF). While researching predictors of the prognosis of MS early in the disease course, I also obtained my Master's Degree in Clinical Research.

**KC: Why did you choose Multiple Sclerosis as your research focus?**

**EM:** I had the privilege of working with Dr. John Wolf at SUNY Syracuse just after I finished high school. It was this experience in my youth that helped shape my interest in multiple sclerosis. As I worked with Dr. Wolf and MS patients, I began to see that although MS could be a debilitating disease, the patients were a young, hopeful group that never stopped laughing or gave up. I knew immediately that I wanted to work with these patients, and I never looked back.

**KC: What MS research will you be conducting at JHU?**

**EM:** I have several studies and research interests. Currently, I am conducting two vitamin D trials. The first is a large trial of vitamin D in patients with MS to see if it helps reduce the severity of the disease. The second is a smaller study in which we are evaluating whether vitamin D is metabolized in the same way in people with and without MS. We will also look at whether vitamin D affects the immune system differently in these two groups. I am also interested in conducting research on gut bacteria and their role in multiple sclerosis. Gut bacteria are inherited primarily from our mother and serve as a "teacher" to the immune system to help it determine what is self and what is not. I am interested in exploring if certain bacteria increase the risk of getting MS or make the disease more severe in those who already have the disease. My overall goal is to study environmental factors that influence MS, especially those that can be changed, and to then determine if changing them makes a direct impact on the disease. It is possible that such factors play a role in other inflammatory diseases of the nervous system as well, so I hope to collaborate with colleagues in the Neuroimmunology/Neuroinfectious Disease division to expand our research to related diseases.

**For more information on Dr. Mowry's vitamin D trials please call 443-287-3704**



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