

## LOOKING FORWARD FALL/WINTER 2014

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Dear Friends,

We hope everyone had a wonderful summer and fall is off to a great start. In this issue of Looking Forward, we have highlighted some groundbreaking research that is currently underway. You will also learn about a recent Colorado trip that was organized by the Johns Hopkins Transverse Myelitis Center (JHTMC) and International Neuro-Rehabilitation Institute (INI) for a group of kids with TM.

In June, the JHTMC held its 2nd annual Regional Transverse Myelitis Symposium, which was very well received. This important event provides educational opportunities for patients, families and caregivers to learn about the latest treatments, rehabilitation strategies and research. Attendees are able to hear directly from physician-scientists who specialize in the diagnosis and treatment of rare neuro-immunologic disorders, such as TM and NMO.

In the Multiple Sclerosis Center, we are excited to share with you that we are in the early stages of a new clinical trial for progressive MS. This trial is made possible through a pilot grant from the Progressive Alliance and we hope to expand the study.

We cannot thank you enough for your support, vision, and commitment as we look forward to another year of meaningful progress in the field of neurology. We are grateful to all of our generous donors as philanthropy provides the support with which we can pursue new research opportunities and provide educational events for the benefit of our patients. Your gifts also allow us to attract and retain brilliant faculty and train the next generation of specialists.

Yours sincerely,

Peter A. Calabresi, MD  
Director, Multiple Sclerosis Center

Carlos Pardo-Villamizar, M.D.  
Director, Transverse Myelitis Center

## FACULTY SPOTLIGHT

ARUN VENKATESAN, MD PH.D.  
ASSISTANT PROFESSOR OF NEUROLOGY



Dr. Arun Venkatesan, MD, PhD is a neuroimmunologist who specializes in the diagnosis and management of encephalitis, multiple sclerosis (MS), and other neuroimmunological disorders of the central nervous system (CNS).

He received his medical degree and PhD in Microbiology and Immunology from the University of California, Los Angeles, before joining the neurology residency program at Johns Hopkins. Upon completion of his residency training, he was a research fellow in the department of Neurology, Division of Neuroimmunology and Neuroinfectious diseases at the Johns Hopkins University School of Medicine, and has since continued in the division as a faculty member. He directs clinical and research activities at the Johns Hopkins Encephalitis Center and is an active member of the Johns Hopkins MS/TM Centers.

Dr. Venkatesan's research interests span both laboratory-based and clinical approaches. His laboratory focuses on identifying therapies that can protect the nervous system in the setting of inflammation. His work has highlighted the importance of targeting the axons, in addition to neuronal cell bodies, for protection, as protection of one without the other can continue to lead to deleterious consequences. His research interests also include delineating the role of microglia and macrophages in CNS inflammation, with a goal of altering microglial/macrophage behavior for therapeutic benefit. His clinical research has focused on identifying prognostic factors and establishing biomarkers in the setting of acute CNS inflammation. More recently, he has teamed up with colleagues in the departments of Neuropsychology and Neuroscience at Johns Hopkins in a multidisciplinary effort to restore cognitive function in those suffering from MS or other CNS inflammatory diseases using a technique called transcranial direct current stimulation (tDCS), which delivers mild currents to the brain in an effort to improve working memory, concentration, and attention; this study is currently enrolling individuals with MS or those who have suffered from encephalitis. Overall, Dr. Venkatesan remains committed to developing and evaluating multiple approaches to help those suffering from CNS inflammatory conditions.

## MY PERSPECTIVE: LIVING WITH MS

MELINDA SMITH



As the patient you can-with explicit detail-relive every significant moment the day your disease first presented itself. This day for me was July 2, 2006. I was bewildered that summer day by the unfamiliar sensations and pain, not realizing I was experiencing my first symptoms of Multiple Sclerosis.

In the beginning, many of my symptoms were transient and much of the testing was inconclusive. Close to a year passed, 25 doctors later and no definitive diagnosis was determined. We were not one step closer to solving this conundrum; I was broken and worn down. I needed a label to adhere to my health issues so I could move forward to help myself. It was a kaleidoscope of negative emotions, and then I found Johns Hopkins.

The professionalism and civility I experienced within the neurology department at Hopkins was nothing short of spectacular. The expertise encompassed the trust and belief I was looking for. Upon coming to Hopkins, I was filled with dread and despair, but left with confidence and reassurance. It would be a new chapter in my life. I was RESTORED. The continuous HOPE and compassion that is displayed within the halls of Hopkins keeps me focused and driven. My attitude, positive and extremely grateful. Eight years has passed since I first met my "Hopkins family". The significant working relationships I have made has enriched my life as we strive to find new therapies for neurological disease.

Experiencing the negative aspects of MS, and for whatever it has taken from me, the life lessons in which I have learned will forever be imprinted. The philanthropic work being done through The Johns Hopkins Project RESTORE is fulfilling and has given me, along with family and friends the privilege of giving back to such an important cause.

## ADVENTURES OF THE JOHNS HOPKINS TM CENTER JHTMC & INI introduce kids to some exciting thrills in Colorado!

MAUREEN MEALY

The Johns Hopkins Transverse Myelitis Center (JHTMC) teamed up with the International Neurorehabilitation Institute to pilot bringing a small group of kids with TM on a week-long adventure this past August in the mountains of Colorado with the coordination of the Adaptive Sports Center. Dr. Daniel Becker (JHTMC/INI), his wife Sharen (INI) and I (JHTMC) were fortunate to have had the amazing opportunity to work with the folks at Adaptive Sports Center to put the week together and experience the adventures right alongside the kids & parents! Based in picturesque Crested Butte, the wildflower capital of Colorado, Adaptive Sports Center (ASC) is an incredible non-profit organization who strives to enhance the quality of life of people with disabilities through exceptional outdoor adventure activities. The successful programs of ASC empower participants in their daily lives and have a positive and enduring effect on self-efficacy, health, independence and overall well-being.

Throughout the week, the group went canoeing & kayaking on scenic Lake Irwin, learned about horse care & the basics of horseback riding at a working ranch, went rafting & kayaking on the white waters of the Gunnison River, and ended the week with a challenging ropes course, which emphasized teamwork, and included a zip line & giant swing among the full day's obstacles. When we weren't taking off on all the adventures, there was time for exploring the wonders of charming downtown Crested Butte (pretty remarkable that one little town can have such unbelievable homemade ice cream & French fries- and boy did we eat- not to mention the natural wonder & kind, inviting residents of the place!).

Everyone participated in the week's activities fully, some having done not one of the activities offered prior to this time. The joy, courage, laughter... and at times, sheer terror that shone on the kids' faces was indescribable as they conquered fears & enjoyed new experiences together during this once-in-a-lifetime opportunity!

JHTMC and INI can't thank ASC enough for facilitating this high-adventure experience and for being a constant source of support throughout our time in Crested Butte, and we hope to be back next year! **For more information on ASC, visit <http://www.adaptivesports.org/>.**

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## FROM THE BENCH

DRS. PETER CALABRESI AND ELLEN MOWRY

A new study, led by Drs. Peter Calabresi and Ellen Mowry, will target progressive MS. The Johns Hopkins MS Center recently received a small pilot grant from Progressive Alliance to begin a clinical trial.

Multiple sclerosis (MS) is a chronic neurological disorder characterized by focal demyelinating lesions in the brain and spinal cord. Involvement of the coverings of the brain and spinal cord (meninges) in the form of abnormal collections (follicles) of certain types of immune cells (B and T-cells) has been described in progressive, and to a lesser extent, relapsing MS. These follicles are associated with increased damage to the adjoining surface of the brain and may play a role in MS progression. Administration of a drug that targets B-cells, such as rituximab directly into the space surrounding the brain and spinal cord through a spinal tap, may disrupt these follicles and hence slow progression.

In this study, we propose to use a special MRI sequence to identify these follicles. In patients who have MRI changes that may represent follicles, we will then perform a pilot study of rituximab given directly into the space surrounding the brain and spinal cord, and will evaluate the safety of this method. We will also evaluate whether there is a response in the size or number of the MRI lesions, or a change in other markers in the fluid surrounding the brain and spinal cord, to suggest reduction in inflammation or damage to brain cells.

This novel trial could be beneficial to patients with progressive MS, who are in acute need of effective therapies. We hope to expand the study if results are positive.

## MOVING UPHILL

### DAWNTHEA PRICE

It started the way many cases do: with blurring vision and confusion. My second day at Girls State—Tuesday, June 16, 2009—began normally, but I couldn't read words with my right eye by lunch.

Two days went by before I told another person, and from there things snowballed: The first ophthalmologist I saw suggested multiple sclerosis and my father drove five hours to pick me up early from the camp at Longwood University. By Friday night, I was in Washington D.C., intravenous steroids in my arm and an MRI on my schedule.

I was 17.

In many ways, the summer and school year that followed was the best, but the worst. After my relapsing-remitting diagnosis on August 20, there were suddenly new restrictions, new fears, new concerns about how to live my life. But, at the same time, I was bolstered by the strong support system my family, friends and teachers provided. When I faltered and was overwhelmed by the strangeness of daily injections, or when I wondered just why this had become my burden to bear, they were there to wipe away tears and offer hugs or help.

There were several obstacles that first year, as I experienced two more attacks before I turned 18, one of which landed me in a Florida hospital on New Year's Day. It was an experience that put a damper on early acceptance to my dream school. For a while, my family wrestled with the potential toll a chronic disease could have on my future if I were to attend a school 800 miles away from that oft-used support system. I was only 17 – how could I climb the insurmountable hill that was university without constant support?

As it turns out, support is not just a physical presence: It is the extra clothes your mother sneaks into your suitcase because you forgot them; the birthday email from your father the first year after graduating from high school; the Skype calls and text messages with those heart symbols. Even when they weren't there, my system found a way to support me nonetheless.

Of course, my family also found ways to make the trip out when I needed them in a more tangible sense, and support from and communication with Dr. Justin McArthur and his staff meant I was consistently cared for. Sometimes, that meant visiting the school clinic for blood tests. Once, it meant flying home to switch medications under Dr. McArthur's watchful supervision.

Without my support system, my family and friends, I never would've felt strong enough to take on the challenges I did. The dream school would've remained a dream, the career to follow an impossibility. Today, I'm able to live my life as fully as possible because these people remain by my side every step of the way.



## A MESSAGE FROM DEVELOPMENT

Project RESTORE was created with a vision to revolutionize the treatment of neuroimmunologic diseases, like multiple sclerosis (MS) and transverse Myelitis (TM). It is a comprehensive and collaborative research effort where clinician-scientists are working to develop new diagnostic and therapeutic strategies in the treatment of these disorders.

Project RESTORE has three goals:

1. REcover function from illness and acute attacks
2. STOp progression of disease and disability
3. REgenerate nerve cells and myelin

For the millions of people living with neuroimmunologic disorders, many of them heartbreakingly young, the consequences can be devastating. So far, treatments to halt the immune attack on the nervous system have only been partially effective. Medicine can slow the process, but, for many, the long-term outcome is the same.

It is our patients who were the motivation behind Project RESTORE as a way to find innovative, promising, focused projects with investigators and scientists who understand that collaboration is a powerful catalyst in developing therapies for MS, TM and other paralyzing disorders.

We hope you enjoy our newsletter, which was written by our faculty and staff to keep you updated on our research and other activities. If you have questions or would like additional information, please contact the development office by phone at 443-287-7877 or by e-mail at [neurodev@jhmi.edu](mailto:neurodev@jhmi.edu).

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If you would like to support our work, simply fill out the bottom portion of this letter and return it in the enclosed envelope.

Enclosed is my check for \$\_\_\_\_\_. (Please make your check payable to Johns Hopkins University and select one of the options below so that we can direct your gift accordingly.)

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