Dear Friends,

In this issue of the Johns Hopkins Project RESTORE Newsletter we highlight the indomitable spirits of our patients and faculty who together are combatting MS, TM and related disorders. “Never Quit” is the battle cry from our friend Steve Moritz as he miraculously pushes his body to complete triathlons despite years of damage to his nervous system caused by MS. His spirit is an inspiration to us all. Others contribute in different but equally meaningful ways such as Kathleen Dodson-Greenberg who patiently allows medical students to repeatedly take a history and perform their first neurological exams on a live patient. Her eloquently written article on this experience is not only inspiring but provides wonderful insight into the world of neurology and health care from a patient’s viewpoint. Her resilience in battling her MS and willingness to keep giving back to the academic community is remarkable and makes all of us work harder to cure the disease. Drs. Levy, Mowry, and Newsome continue to lead the outreach mission to the community by unselfishly donating their time to give educational talks to the public. Dr. Levy’s NMO patient day was a huge success. All of our physicians and scientists never forget the people whom we serve. This spirit is contagious and motivates our researchers to come up with new ideas and approaches for repairing the damage. The Calabresi team continues to make promising discoveries in the lab that they hope will enhance the body’s own capacity to repair myelin. One of these drugs is already being tested in a clinical trial led by Dr. Newsome. We are all in this together and remain ever hopeful that as a team we will develop therapies to relieve the suffering brought on by MS, TM and other neuroinflammatory diseases.

Yours sincerely,

Peter A. Calabresi, M.D.
Director, Multiple Sclerosis Center

Carlos Pardo-Villamizar, M.D.
Director, Transverse Myelitis Center
Dr. Scott Newsome is a neuroimmunologist who specializes in the diagnosis and management of people with multiple sclerosis (MS), transverse myelitis (TM), neuromyelitis optica (NMO), stiff person syndrome (SPS) and other neuroimmunological disorders of the central nervous system.

He received his medical degree from the New York College of Osteopathic Medicine and graduated with honors before completing his internship in internal medicine and residency in neurology at Albany Medical Center in New York. After finishing neurology residency, he went on to complete a research fellowship in the department of Neurology, Division of Neuroimmunology and Neuroinfectious diseases at Johns Hopkins University School of Medicine with the support of a Sylvia Lawry Physician Fellowship from the National Multiple Sclerosis Society. Upon completing this fellowship, Dr. Newsome joined the faculty within the division and is currently the director of the Johns Hopkins Neurology Outpatient Services and the Neurology Infusion Center.

Dr. Newsome’s main research has focused on validating specific quantitative clinical outcome measures in MS and determining the extent that these measures detect abnormalities over time and relate to global disability measures/ambulation in MS. These tools may improve the precision of disability measurements in MS and other central nervous system disorders and may be used in future neuroprotective/neurorepairative medication trials.

Dr. Newsome is also one of the main clinical trialists within the division and is currently the principal investigator for several very important multi-center MS and NMO clinical trials, including the Anti-LINGO-1 (putative remyelinating agent) trial in MS. He was recently awarded a research grant from the National MS Society to conduct a phase 1 study that he designed to evaluate the safety and tolerability of another putative remyelinating agent, liothyronine, in individuals with MS. This study along with others is helping to build the experimental therapeutics program within our MS center.

Additionally, he is in the process of building an SPS research program in hopes of gaining further insights into this disease, so targeted therapies can be developed. His collection of SPS biosamples will be used for immunological studies. He also started, “The Johns Hopkins Stiff Person Syndrome Working Group”, whose mission is to build a comprehensive longitudinal database of SPS patients for future and ongoing research initiatives.

I’ve always loved a good challenge, but being diagnosed with progressive MS twenty-four years ago was a bit more than I was prepared for. While I attempted to stay physically active, the ensuing years were frustratingly typical as my athletic capabilities eroded over time. I reluctantly accepted the reality that my years as an active sports junkie were probably over.

However, thanks to the proactive care provided to me by the Hopkins Neurology Department and the breakthroughs in research engineered by Project RESTORE, I was able to realize an atypical physical renaissance about eight years ago. And so I found myself thinking about a radical self-challenge: why not try to complete a triathlon?

My pre-MS lifestyle included a broad spectrum of athletic endeavors – distance running, soccer, tennis and golf, but I’d never participated in a triathlon. So, I began training for all three legs of the triathlon: swimming, biking and running. The training regimen was tough and I often found myself wanting to quit. However, my three daughters had always been taught that it was unacceptable to quit anything after having made a commitment. Being the case, I had no choice but to continue through the pulled calf muscles, exhaustion and occasional falls.

After three years of training, I was ready to do my first triathlon in June of 2009. As luck would have it, the temperature that day was over 100 degrees, but I did finish: much closer to last than first. I was once told that there’s more courage in finishing last than first. I now fully understood that concept!

I’m now in my fifth triathlon season and have completed fourteen competitions, but this fall I will try an even more interesting challenge. I am associated with Athletes Serving Athletes (ASA), an organization that assists disabled children to participate in triathlons and marathons. In collaboration with my daughter Jacqueline (who started doing triathlons with me two years ago), we will pull and push a young man with Cystic Fibrosis through the Baltimore Triathlon on October 4th.

Most people with MS are not as fortunate as I. I’ve had a great support system that’s really helped me stay active. The cornerstone of that system remains the brilliant and compassionate caregivers from Hopkins and Project RESTORE. They know too that quitting is not an option.

Steve is a member of the Board of Ambassadors of Project RESTORE. He is committed to the work of Johns Hopkins Neurology and the mission of Project RESTORE.

Story & Photo provided by Steve Moritz
One day this past spring, I arrived at the Johns Hopkins Outpatient Center for an appointment. I took the elevator (going down to go up, of course, in case anyone doesn’t already know that trick) and checked in at the reception desk. A clinic assistant ushered me through a corridor, framed on one side by floor to ceiling windows overlooking the iconic dome – which is breathtakingly beautiful and a sight I had never before seen – and into an exam room. I set aside my orange Sabi cane, turned off the transmitter on my Bioness, climbed up on the examination table, and waited.

After a brief commotion in the hall, a group of six 20-somethings – all wearing slightly longer than waist-length coats – streamed into the exam room. Some were quiet and shy; others, quick to extend a hand. Accompanying the “Student Doctors” was a more senior doctor, who invariably introduced him or herself by first name and who was wearing a longer coat. A noticeably longer coat. Practically knee-length.

For the next two and a half hours in 40-minute segments, small groups of first-year medical students – under close observation and helpful direction by a member of the Johns Hopkins Neurology Department – took their Neurology Clinical Exams at the Johns Hopkins Simulation Center.

“These young people are the future generation of doctors. ... Maybe even a few will specialize in MS. ... Maybe one of them will find a cure...”

Using a tag team approach, the students conducted a neurology exam: mental status, cranial nerves, motor and sensory systems, reflexes, coordination, gait – all tests that I, like many of you, could do with my eyes closed (which sometimes I did, in an effort to prevent myself from helping). Very quickly, I got 23 years of history down to a short and entertaining paragraph. My brisk and pathological reflexes were particularly affirming; even those first-years who purported to have difficulty with the triceps reflex scored points with mine. (“Make sure you save time to check my reflexes: Hoffman, Romberg, Babinski. I’ve got them all.”)

For the final half-hour, the exams were conducted in ten-minute “Speed Date” (the JHM term, honestly, not mine) sessions. The students would charge in and quickly make an effort – through a combination of history, evaluation and gut instinct (with a hint or two from the neurologist at hand) – to determine my disease.

I spent three days as a model patient. It was a blast. The students – who began the first week reserved and reticent – were, by the end of the second week, outspoken and confident. I was especially proud that the student body was not only extraordinarily sharp, but also an equal combination of women and men as well as a diverse mix of cultures.

Other members of the Project RESTORE Board participated as well, including Mark Barondess and Thomas Schrader. Mark observed, “What an impressive group of ‘kids.’ They are compassionate, inquisitive and brilliant, excited and ready to pursue the challenges of becoming tomorrow’s top docs.” Tom commented, “I found the model patient program to actually be quite enjoyable. The students were very impressive, but a little uptight, so it was fun to get them to laugh and loosen up while still helping to teach them about my condition. I look forward to another round next year.”

There were so many MS patients willing to represent, the neurologists in charge of the program – Dr. Thomas Crawford and Dr. Nicoline Schiess – had to cull through our ranks one day. That was the day that Drs. McArthur, Calabresi and Newsome – the venerable team from the MS Clinic – were shepherding students through the halls. (Just as well. Too much pressure.)

One thought kept running through my head as the door to the exam room opened and each new group of students entered. These young people are the future generation of doctors. Maybe some will choose to study Neurology. Maybe even a few will specialize in MS. Maybe one of them will find a cure (unless Johns Hopkins Neurology has already accomplished that feat). Right now they have a lot to learn, but, in a few short years, they will be the leaders – and wearing the much longer coats.

Kathleen is a member of the Board of Ambassadors of Project RESTORE. She and her husband, Eric, are deeply committed to the work of Johns Hopkins Neurology and the mission of Project RESTORE.
The Johns Hopkins NMO Clinic hosted their second regional Neuromyelitis Optica (NMO) Patient Day on August 30. This event, sponsored by the Guthy Jackson Charitable Foundation, included more than 160 guests who heard from a wide array of experts discussing the diagnosis and treatment of NMO. The potential to change this situation lies in the discovery that all of us have in our brains and spinal cords a type of cell called an oligodendrocyte precursor cell (OPC), which is a progenitor cell that on its own doesn’t produce myelin, but possibly can be coaxed into becoming mature myelin producing cells. It was previously thought that these cells only functioned in early development of the brain and were not present in substantive quantities in adults. However, results now show that OPCs are indeed present in adults, and importantly, they can help repair myelin even years after normal myelination of early childhood is completed. In MS, there is no shortage of these cells, but they often don’t seem to mature and make myelin as efficiently as we would like. Together as a team, we are studying these cells with the hope of understanding how to turn them on and drive them into becoming mature myelin cells that will repair the myelin. One revealing lead is that thyroid hormones are critical for myelination and thyroid analogues that preferentially work in the brain, may be one way to induce these cells to initiate myelin repair. The team is screening other compounds that wake up the precursor cells and tell them it’s time to make more myelin. We can get cells to make myelin in a tissue culture dish using several FDA approved drugs for other medical conditions, and we are hopeful that this strategy can be rapidly translated to the clinic. Dr. Newsome is already testing the safety of a conventional thyroid replacement compound, called T3, in the clinic. The team anticipates that combinations of drugs may make the myelin repair process more efficient. The goal is to have drugs that not only stop the inflammation attacks, but also to RESTORE the myelin so people can function better.

Research Story by Peter Calabresi, M.D.

NMO PATIENT DAY

As people living with MS know, repairing the myelin damaged by the disease has been an elusive goal. Exciting results from recent research may bring us closer to being able to do just that, however. Myelin is produced by special cells in the brain called oligodendrocytes. When these cells are killed by disease, they cannot produce the myelin needed to repair damaged axons, and thus disease progresses. The potential to change this situation lies in the discovery that all of us have in our brains and spinal cords a type of cell called an oligodendrocyte precursor cell (OPC), which is a progenitor cell that on its own doesn’t produce myelin, but possibly can be coaxed into becoming mature myelin producing cells. It was previously thought that these cells only functioned in early development of the brain and were not present in substantive quantities in adults. However, results now show that OPCs are indeed present in adults, and importantly, they can help repair myelin even years after normal myelination of early childhood is completed. In MS, there is no shortage of these cells, but they often don’t seem to mature and make myelin as efficiently as we would like. Together as a team, we are studying these cells with the hope of understanding how to turn them on and drive them into becoming mature myelin cells that will repair the myelin. One revealing lead is that thyroid hormones are critical for myelination and thyroid analogues that preferentially work in the brain, may be one way to induce these cells to initiate myelin repair. The team is screening other compounds that wake up the precursor cells and tell them it’s time to make more myelin. We can get cells to make myelin in a tissue culture dish using several FDA approved drugs for other medical conditions, and we are hopeful that this strategy can be rapidly translated to the clinic. Dr. Newsome is already testing the safety of a conventional thyroid replacement compound, called T3, in the clinic. The team anticipates that combinations of drugs may make the myelin repair process more efficient. The goal is to have drugs that not only stop the inflammation attacks, but also to RESTORE the myelin so people can function better.

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**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.

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

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Restoring hope, function, and lives to MS & TM patients

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