Dear Friends,

Happy Spring!

In this issue of the Johns Hopkins Project RESTORE Newsletter we are excited to share recent advances in research which are improving lives of people living with multiple sclerosis, transverse myelitis and related disorders.

We introduce you to a new member of our faculty team, Meghan Beier, a neuropsychologist who practices acceptance and commitment cognitive therapy to help patients develop tolerance for living with MS.

Kathy Zackowski and her collaborative team at KKI’s Center for Movement Studies introduces an innovative exercise training program using only elastic resistance bands that has demonstrated improvement in hip and leg strength in 8 weeks.

We share the inspiring story of Joseline, a young woman, who despite the frightening and sudden onset of transverse myelitis embraced the rigorous therapy regime and has made great strides in her rehabilitation.

We also highlight the Pardo team’s collaborative efforts to explore the link between Zika and neurological problems such as Guillain-Barré Syndrome and myelitis with the launch of Neuroviruses Emerging in the Americas Study (NEAS) web based observatory for neurological disorders.

Thank you for your continued support of our efforts to relieve the suffering associated with neuroinflammatory diseases.

Yours sincerely,

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

Carlos Pardo-Villamizar, M.D.
Director, Transverse Myelitis Center
When coping with chronic medical conditions, patients wonder, “What is going to happen next?” and “When exactly will it happen?” Meghan Beier, a neuropsychologist who specializes in multiple sclerosis (MS), finds that patients often present as depressed or anxious because of the uncertainty of living with MS, a disease hallmarked by ambiguity.

“They never know if there is going to be an exacerbation, how severe the symptoms will be or how fast the symptoms will progress,” Beier says. “Data shows that 85 percent of people with MS have periods of stable health followed by an episode of worsened symptoms that may or may not fully remit.”

In a 2015 paper, Beier examined the concept of intolerance of uncertainty, or IU, and how it relates to MS. IU is the idea that individuals who have difficulty tolerating the possibility of a future negative health occurrence also have worse psychological outcomes.

In a review of the literature on IU, Beier found that people with medical conditions, such as cancer, and who scored high on the continuum of the Intolerance of Uncertainty Scale, had more worries about their health, higher health anxiety and increased threat perception.

“Because uncertainty is an inevitable part of the MS experience, being able to cope with such concerns is central to the psychological well-being of MS patients.”

Because so many aspects of a patient’s life can be affected by living with MS, the multidisciplinary team approach at The Johns Hopkins Hospital allows treatment from many different angles. Beier coordinates with psychiatrists, neurologists and physiatrists, as well as physical, speech and occupational therapists, on a regular basis to provide comprehensive care for patients with MS.

Meghan Beier, Ph.D. is a Rehabilitation Psychologist and Clinical Researcher specializing in multiple sclerosis (MS) at the Johns Hopkins University School of Medicine. Dr. Beier obtained her Ph.D. from Yeshiva University. She also completed a National Multiple Sclerosis Society Fellowship in the Department of Rehabilitation Medicine at the University of Washington. Her research and clinical focus is the cognitive and emotional symptoms common to multiple sclerosis.

This article originally appeared in the Winter 2016 issue of Restore, a publication of the Johns Hopkins Medicine Physical and Rehabilitation Department.
Joseline Castillo had a dream — a young American with roots in Central America, she had grown up in the Dominican Republic but had plans to spend her senior year in high school living with family in the US and apply to college to study architecture.

However, one morning in February 2015, Joseline woke up with a mysterious illness and had trouble moving. “It happened in a matter of a few days,” she recalls. It started with a weird tingly feeling in her legs and a severe headache and the following day she realized she did not feel anything below her waist and could not move her right leg. Her symptoms gradually got worse and she lost her ability to walk. Joseline was just 17.

After days of diagnostic tests, Joseline’s doctors came to the diagnosis of transverse myelitis. Joseline and her family were terrified. After meeting with neurologists in Santo Domingo her family made the decision to have Joseline move to the US to be treated at The Johns Hopkins TM Center. She would live with her aunt and cousin in Washington, DC. She arrived in April for her initial assessments with Dr. Pardo and the team at Kennedy Krieger Institute (KKI). She spent most of the next three months as an in-patient undergoing intensive therapy with the goal of rehabilitation to a wheelchair. Following her discharge in July she continued her recovery as an outpatient traveling to Baltimore several times each week. During this time she stayed focused on her dream — completing her junior year course of study. When Joseline came back for her follow up appointment in the Summer of 2015, Dr. Pardo was quite impressed and excited to see her progress. He told her “the best way to achieve your goal to get into college was to keep up your high level of "Vitamin P" — plenty of passion ... plenty of positivity!”

This past August she started her senior year at Woodrow Wilson High School in Washington DC and is on track for graduation in June with plans to enroll in Drexel University in the fall. She continues her physical therapy two days a week and she is excited to share that she can now get around on crutches without needing her wheelchair!

Joseline is very grateful for all the support she has received and shares that having a support system is very important. Joseline says that she doesn’t let her disability keep her from living a normal life: “I don’t see my disability as something that deprives me of doing something. It just makes me do things a new way.”

Story and photo provided by Joseline Castillo

Joseline(left) with Liza, her therapist of Kennedy Krieger Institute, after finishing the 5K race at the Baltimore Running Festival

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Story and photo provided by Joseline Castillo

UPCOMING EVENTS

Biennial Golf Event / Mon May 2nd
MULLIGANS FORE MS, Burlington, N.C.
Contact: melindasmith1@att.net

4th Annual JHTMC Regional TM Symposium
9 am – 5 pm / Sat June 25th
JOHNS HOPKINS HOSPITAL Conference Center Zayed 2117
Contact: hopkinsTMcenter@jhmi.edu

Hockey Fights MS Tournament / June 3-5th
Laurel, MD / Contact: info@hockeyfightsm.org

Climb for Hope Expedition
July 10 – 16th Mt. Adams, Washington
August 18 – 22 Mt. Rainer, Washington
Contact: Andy Buerger, INFO@CLIMBFORHOPE.com

A Day for Families Living with MS Workshop
10 am – 2 pm / Sat December 3rd
JOHNS HOPKINS HOSPITAL Conference Center Zayed 2117-2119
Contact: semrich1@jhmi.edu
University-based centers and researchers in areas affected by the epidemic in Colombia moved fast to set up a study to collect fluid samples – blood, saliva, urine and spinal fluid from patients with neurological problems. While the typical blood test to check for Zika antibodies is a challenge because the virus tends to cross react with similar viruses that many people in the region have already been exposed to – including dengue and Chikungunya, leading to a false positive test for Zika. Additionally, checking the person’s blood for the presence of Zika virus itself is difficult because the virus can only be found in the blood during a short period of infection. However, research suggests Zika might linger longer in other bodily fluids.

On March 1st, they launched the Neuroviruses Emerging in the Americas Study (NEAS) web-based observatory for the neurological disorders. The site contains information about the virus and neurological complications but also provides a platform for all health care providers in Colombia and the Americas to learn about the diagnosis and management of the neurological complications in the viruses. The website will also be the repository for the main research centers in the field to deposit the clinical and lab data.

Worthy to note in this effort: despite concerns and massive media coverage about Zika, no federal support is available at the moment for this type of research. We were able to move forward with funding from private philanthropy through Johns Hopkins Project RESTORE and the Bart A. McLean Fund for Neuroimmunology Research.

Late in December, Dr. Carlos Pardo-Villamizar received a call from his colleagues in Colombia describing an unusual onset of paralyzing neurological disease cases – later it was evident these were cases of Guillain-Barré Syndrome (GBS), a few with Transverse Myelitis. GBS occurs when a person’s immune system starts attacking their nerve cells, causing temporary paralysis. People can lose the ability to walk, to smile, even to breath. Similar cases have been reported in four other countries where Zika is spreading in a big way. He quickly made the connection that this may be related to Zika.

Dr. Pardo’s team at Johns Hopkins and collaborators through a network of

For additional information visit www.neasstudy.org

For many people with multiple sclerosis (MS) maintaining the ability to walk is critical to quality-of-life. Hip weakness affects walking speed, particularly in the weakest individuals, and often leads to increased disability. New research from Kathy Zackowski’s laboratory at the Kennedy Krieger Institute’s Center for Movement Studies shows how an exercise training program using only elastic resistance bands can improve hip and leg strength in 8 weeks. The bands are a convenient and affordable alternative to more traditional, costly gym equipment that is not always accessible. The program can be successfully adapted for individuals with variable levels of disability. Our collaborative team developed an instructional manuscript, published in the Journal of Visualized Experiments that is available to patients, therapists and caregivers. These are valuable in motivating participants who often want to know when to expect to see improvement from their rehabilitation efforts.

Watch the video at http://www.jove.com/video/53449

Story by Kathleen Zackowski, Ph.D., OTR
Project RESTORE was created with a vision to revolutionize the treatment of neuroimmunologic diseases like multiple sclerosis (MS), transverse myelitis (TM) and neuromyelitis optica (NMO). 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 Kaylin Kopcho, our development officer, by phone at 443-287-7871 or by email at kaylin.kopcho@jhmi.edu.

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

www.hopkinsmedicine.org/neuro
Email: projectrestore@jhmi.edu