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Letter from the Co-Directors

Dear Friends,

Our cold and snowy winter is finally past and the flowers of spring are in bloom. I think we all feel rejuvenated as the days become longer, and the sun a little warmer. Spring is a time of hope and a time for “looking forward”.

In this issue of “Looking Forward” we highlight our Transverse Myelitis (TM) Center. Our Center was established in 1999 and with the addition of Maureen Mealy, RN, BSN as the Program Manager for the TM Center, patients have better access to our Center and the many services that are offered. Most importantly, Maureen is an accessible contact person who is both compassionate and knowledgeable about this rare disorder. Linda Beck, an individual diagnosed with transverse myelitis, shares her story in this issue and how the TM Association and the Johns Hopkins TM Center were able to help her as she went through her devastating illness.

Through a new collaboration with the Kennedy Krieger Institute, we now have physical therapists who attend the TM Clinic where they can assess individuals during their clinic visit and can make recommendations for further care. A number of research trials are also underway to better understand and treat transverse myelitis.

In this issue, we also feature Kathleen Zackowski, PhD who is conducting research on mobility. First, she is trying to establish improved assessment tools to measure functional abilities. In addition, she hopes to utilize specialized MRI techniques to identify areas of myelin and nerve damage not seen on conventional MRIs and determine if these changes might predict future problems with mobility. The goal of this research is to identify problems before they become permanent and allow intervention with new therapies and help guide the type of physical therapy program that a patient may benefit from the most.

Finally, we hope you enjoy the photos from our annual fundraising event. This year, we participated in the Fallston Duathlon; a run – bike – run event. Thus far this event has raised \$60,521.00 for Project RESTORE. We thank all who participated in the event and those who contributed so generously to Project RESTORE. A very special thanks to Tom Schrader who donated \$20,000.00 to Project RESTORE.

With appreciation for your continued support,
Peter Calabresi, MD and Carlos Pardo, MD

THE JOHNS HOPKINS TRANSVERSE MYELITIS CENTER, ONE DECADE OF WORK AND THE CHALLENGES FOR THE FUTURE.

BY MAUREEN MEALY, RN, BSN & CARLOS A. PARDO, MD



Johns Hopkins TM Center Team

What's new?

- We have improved our ability to interact with patients and physicians by facilitating easy and rapid communication. With the support of Maureen Mealy, RN, BSN, Program Manager of the JHTMC, we have established easy access to patient referrals and an expedited consultation process.
- We have established a system to facilitate a comprehensive assessment that involves not only the neurological evaluation, but other types of consultations in an effort to provide patients with long-term plans for management of all health problems associated with TM. This system has been put into place in an effort to provide patients with the best opportunity to get the absolute most out of their visit in a more timely fashion.
- The JHTMC is comprised of a team of neurologists within the Neuroimmunology Division at JHH, led by the JHTMC Director Dr. Carlos Pardo-Villamizar, who have a specialized knowledge of this rare disorder. Each of these physicians have their own subspecialty, including acute management of TM, neurorehabilitation following TM, and neuromyelitis optica to name a few.



Maureen Mealy, RN, BSN

What's new in research?

- The Accelerated Cure Project is a multi-center central blood repository and database which allows us to investigate causes, diagnostic methods, therapies, and eventually cures for demyelinating disorders of the central nervous system. These data are made available in a de-identified manner to researchers from around the world to help each of them with their individual efforts. It requires participants to fill out a questionnaire and contribute a blood sample. Please contact Gita Byraiah at 410-502-6160 or gbyraia1@jhmi.edu for more information.
- Johns Hopkins is currently enrolling new and recently diagnosed patients with idiopathic acute transverse myelitis (IATM) to study risk factors for the disease. In this study, patients complete a questionnaire detailing demographic data and their full medical history of the preceding 24 months prior to the onset of idiopathic acute TM. Interested patients should contact the study coordinator Ms. Maureen Mealy (410-502-8672).
- Volunteers with transverse myelitis, multiple sclerosis, or NMO needed to study the effect of Functional Electrical Stimulation (FES) cycling on factors in blood and spinal cord in people with history of spinal cord inflammation as seen in TM, MS, and NMO. FES cycling is a method of applying low level electrical currents to the leg and buttock muscles to cause the weakened or paralyzed muscles to contract and produce a cycling motion of the legs. Please call the ICSCI Clinical Research Coordinator at 443-923-9235 or email clinicaltrials@spinalcordrecovery.org for more information.
- Other studies include a series of research studies being done in neuromyelitis optica. Currently, these studies include serum-based biomarker studies, vitamin D research, and optical coherence tomography studies. Research is also being done in depression and gait dysfunction in TM.

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LIFE WITH TM: A PATIENT'S STORY

LINDA E. BECK

Seven months ago on September 17, 2010, I ended up in the first of four hospitals for the next forty nine days. I have Transverse Myelitis – what a nightmare. My life has changed horribly. After my hospitalizations, my daughter was on the computer looking for some kind of information on TM, and thank goodness she found The Transverse Myelitis Association – she emailed Sandy Siegel. When I ended up speaking with Sandy he was able to put me at ease and helped me to realize that I am not alone in this life-long battle with TM. In the hospital not many people had ever heard of TM, so I am grateful that Sandy was able to send me a lot of information on this terrible disease. This information led me to the Johns Hopkins Transverse Myelitis Center.

I went to Johns Hopkins for my appointment where I met with the experts Dr. Carlos Pardo and Maureen Mealy, RN. There aren't many doctors and nurses who have such a great bedside manner anymore like they do. Even since my visit, I have been able to speak with Maureen on so many occasions about my disease – she is very courteous, friendly, and has patience with me in this troubling time in my life. She explains the medicines, vitamins, and exercises that help me – I truly believe she understands how I feel. I know I am three states away but I feel very comfortable calling Maureen. She truly is an expert.

Recovery has been slow, and I have had my share of problems along the way. But, I just have to think back to not even being able to walk when I was in the hospital, and it reminds me of how far I've come. I'm thankful that Dr. Pardo and Maureen have been there to help me along the way and have pushed me to stay positive when it hasn't always been easy!



MRI showing longitudinally extensive transverse myelitis lesion

STEPS TO IMPROVE WALKING IN MS

KATHY ZACKOWSKI

Within ten years of being diagnosed with MS, a majority of people will experience disability, most often due to walking impairments. Pharmacologic treatments currently available offer protection from new attacks but do not directly help with recovery. Many people with the relapsing forms of MS will recover from previous attacks; however, some do not and disability accumulates over time. Individuals with progressive forms of MS continue to accrue disability with no clear drug therapy to stop the progression. New medications are critically needed to stop the accrual of disability. As the cause(s) of MS are poorly understood and there is no curative treatment there is a glaring need for more knowledge about symptoms and more effective rehabilitative approaches for individuals with MS.

In the Center for Clinical Research at the Kennedy Krieger Institute we are approaching these issues by working to develop more sensitive ways to quantify common symptoms of MS, such as strength and sensation. To do this we capitalize on the strengths of our motion laboratory which has tools to quantitatively measure ataxia, sensation, and muscle strength impairments that contribute to walking disability which we think will provide a faster means of evaluating success of drug and rehabilitative trials for people with MS.

Our other line of research is to test different rehabilitative techniques using the tools we have in our laboratory and determine how and why walking improves in people with MS. Common intervention studies measure the primary impairment (e.g., strength) with little or no consideration for other impairments (e.g. sensory loss) and any effects on more complicated movements (e.g. stair climbing). Since MS varies from patient to patient, it would be helpful to know which individuals are more likely to benefit from resistance training and which may be more effectively treated with balance training or compensatory techniques.

One way to learn more about this is to use our quantitative measures of strength and sensation in combination with magnetic resonance imaging (MRI). Standard MS care uses MRI for diagnosis, identification of inflammatory lesions, and to determine treatment efficacy. Conventional rehabilitation relies on clinical judgment using rating scales and impairment measures to determine treatment efficacy. We would like to understand how behavioral impairments (i.e., strength and sensation) and MRI findings relate to each other, and use this information to predict who might be most responsive to a resistance strength training intervention.

In summary, our goals are to (1) develop more sensitive outcome measures which could be used for optimizing the effects of future neuroprotective drugs in MS, and (2) to develop a scientific basis for using training interventions, based on biologic principles to guide rehabilitation for people with MS.



The Johns Hopkins
RESTORE TEAM



On Sunday May 1, 37 individuals participated in the Fallston Duathlon and helped raise awareness and funds for Project RESTORE. The weather was cool and slightly overcast, making for a perfect race day. Some of the participants were members of teams, while others completed the entire race (5K run - 19mile bike - 5Krun) alone. Dr. McArthur, the Chair of the Hopkins Neurology department completed the entire race alone, while Drs. Calabresi (Director of the MS Center), Levy (Director of the NMO Center), and Pardo (Director of the TM Center) each participated as members of two or three person teams. Project RESTORE Board member Steve Moritz participated with his two daughters; he biked the 19 mile leg of the race, while his daughters each ran the 5 K's.

The Project RESTORE banner was proudly displayed on our team tent. Kathleen Greenberg and her husband provided refreshments for all.

We had many "cheerleaders" urging us on and congratulating us when we crossed the finish line. And thanks to Steve Moritz and his wife, all participants were clad in Project RESTORE team jerseys.

Project RESTORE teams comprised nearly 1/3 of all race participants! We hope to participate again next year - with an even greater team presence.

A huge **"THANK YOU!"** to all who raced and to all who provided their support to the participants and to the event. Special thanks to Steve Moritz, whose enthusiasm for the event was unsurpassed, and whose guidance clearly helped to make the event a huge success. Also, huge thanks to the event committee of Steve Moritz, Kathleen Greenberg, Chris Glick, Kathy Costello and Peter Dziedzic.

**FROM DEVELOPMENT:
FUNDRAISING
ACCOMPLISHMENTS!**

Duathlon - \$60,521

This fiscal year, 7/1/10 to 4/25/11, we have received \$892,739 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!



The Johns Hopkins Project RESTORE

Donors may be recognized in our publications. Please print your name as you wish it to appear, including your preference for Mr., Ms., Mrs., Miss. Ms. or if you wish to remain anonymous.

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

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Project RESTORE strives to restore hope, restore function and restore the lives of patients and families suffering with transverse myelitis or multiple sclerosis. This project funds researchers to work together to discover new biological indicators of neuroimmunologic diseases, develop new imaging strategies, and conduct clinical trials to support the creation of progressive treatments.

Transverse myelitis (TM) and multiple sclerosis (MS) are the two primary disorders our team focuses on. Both disorders attack and injure the nervous system. Although considered rare, more than 2.5 million people suffer with TM and MS worldwide. Research efforts have been limited due to limited numbers of patients at each Center. Project RESTORE strives to accelerate this progress. Our strategy enables us to attract patients from all over the world to not only treat, but to compile the necessary data to identify common symptoms and causes and develop and offer clinical studies. Project RESTORE is a collaborative effort between our multiple sclerosis and transverse myelitis centers.

At Johns Hopkins, we believe that without collaboration, money and effort are not spent efficiently, brilliant research is not optimized and progress is slower than it needs to be. Our goal remains to help researchers receive the needed financial support to accelerate the discovery and testing new therapies.



The Johns Hopkins
PROJECT RESTORE
Restoring hope, function, and lives to MS & TM patients

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