



Multiple Sclerosis News

Winter 2010-2011

Multiple Sclerosis Comprehensive Care Center at Stony Brook
National Pediatric MS Center at Stony Brook University Medical Center

**The National
Pediatric MS Center
at Stony Brook wishes
you and your loved ones
a 2011 filled with
hope and promise.**



 **STONY BROOK
UNIVERSITY
MEDICAL CENTER**



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Advancing Research

Progress in the understanding and treatment of MS is clearly marching forward. This fall, the first oral therapy became available for modifying the disease course in MS. The medication, Gilenya, has already been used by many individuals but others are either content with their current treatment or waiting for some more time to elapse before considering it. Also in October was the international meeting of the European Committee for Treatment and Research In Multiple Sclerosis (ECTRIMS). Advances in defining the environmental risk factors underlying MS such as sunlight exposure, vitamin D intake, and exposure to smoking were reviewed. Vitamin D levels are most influenced by sunlight exposure and next by diet. More than 80% of adults have low vitamin D levels, so supplementing with this vitamin might be helpful to all individuals. The risk factors identified for adults with MS also apply to children. For example, children exposed to passive smoke are at increased risk for MS compared to those children without such exposure.

Other information discussed at ECTRIMS was yet more new MS treatments under development. For example, the medication Ocrelizumab, is a treatment that only requires administration by vein twice, given two weeks apart, every 6-12 months. Tested at two different doses, the medication reduced relapse rate by 70% at the lower dose and 80% at the higher dose. No increased risk for infection was found between the active and placebo groups.

Since the conference other meetings have occurred in which researchers from all over the world have gotten together to wrestle with critical issues in MS. The International Pediatric MS Study Group convened in London. This group, founded in 2002 by Dr. Krupp, involves members from all over the world including Australia, Africa, South America, and North America. A research project to examine the relations between viral exposures and other MS risk factors as they affect children will soon begin. The group also prepared a consensus statement that will go to the Federal Drug Administration designed to make it easier to study in children the new medications under development and to make sure they are equally safe and effective as they appear to be in adults.

One very important area that still requires further work is better therapies for those with the progressive forms of MS. Dr. Krupp and others met in a small international gathering with members of the academic community, pharmaceutical companies, and the National MS Society. The goal was to share what we currently understand about primary and secondary

please turn to page 2

SPOTLIGHT ON STAFF



Patricia Melville, RN, NPC

Patricia Melville began her nursing career at Stony Brook in 1979 in the ICU unit. Dr. Lauren Krupp inspired her to specialize in multiple sclerosis 15 years ago. Pat, now a nurse practitioner, expertly cares for the many patients that pass through the MS Comprehensive Care Center at Stony Brook.

Pat is the founding force behind the newly opened Infusion Center at Stony Brook and is now working on developing a new Spacticity program. She is involved in many MS clinical trials and patient education programs. Pat fosters a team approach to making treatment decisions. "MS is a challenging disease and I feel privileged to work with patients that live with this challenge every day", says Pat.

2010 Teen Adventure Camp



Excitement was in the air as we began our 2010 Teen Adventure Camp. This summer we reached out to our 100th teen with MS.

Once again happy voices echoed across the lake from the basketball courts to the camp fire circle as returning campers caught up with old friends and our first time campers experienced the "camp magic". Activities included the High Ropes course, Kayaking, camp fires, a talent show, swimming and sailing in Newport Harbor. As a camper from California said, "This is the one place where we can all fit in and everyone understands". A newly diagnosed young man from the Bronx remarked that he had "found a new family".

Our mentors, young adults who had been campers in earlier years, returned to share their experiences. Topics included how to stay compliant with treatments over time; communicating with your health team; and sharing your MS diagnosis with others including friends, teachers and the work place. We learned the importance of communication and strategies were developed by the campers and modeled by all.

The positive effect of camp continues long after campers go home as they stay in touch through emails, Facebook and texting. Be on the lookout for information about a camp reunion in Manhattan January 15th. Plans for camp 2011 are in motion and we can all look forward to another amazing summer!

*Interested in attending the Summer 2011 Teen Adventure Camp?
Contact Maria Milazzo at 631-444-7802.*

Advancing Research *(continued from page 1)*

progressive MS and to work together to develop better treatments. New models are being tested to unravel how inflammation interacts with neuronal degeneration. Once these questions are answered we will be further along in developing therapies aimed at neural protection and repair.

In summary, treatments for MS are being developed at a rapid rate. The risks for developing the disease are becoming better understood. Children, an under-recognized subpopulation with MS, are now being studied,

are diagnosed more quickly, and are getting on to the treatments they need more rapidly.

Finally, we are focusing in a very serious way on developing strategies to halt disease progression. At our adult and pediatric MS Centers we continue to participate in collaborative research, provide multi-disciplinary services, and have the wonderful opportunity to interact with members of the community who share our passion to cure MS.

HAPPENINGS

Summer Soiree



Honoree Ron Rizzo and Merry Slone, founder, are joined by the entire Summer Soiree Committee



Dr. Lauren Krupp, Founder, Merry Slone, and Dr. Steven Strongwater, Stony Brook Hospital President

CROSSFIRE CONFERENCE



Left to right, Pat Melville, Dr. Pat Coyle, Ruth Mahnken, Dr. Lauren Krupp

Harvest Luncheon



Left to right: Lisa Lourie, Jo Biederman, Mary McCarthy and Vera Kiernan



Left to right: Lauren Kaushansky, Joan Lash, Joan LeBow, Dr. Lauren Krupp, Elaine Strongwater, Barbara Delfyette and Gloria Synder

Special Thanks

The National Pediatric MS Center would like to thank all of its donors and supporters in 2010. Your involvement makes it all possible.

A Special Thanks to Country Music Star Clay Walker for his generous support and tireless efforts on behalf of the National Pediatric MS Center.

**Believe
in a world
free of MS**

Make your tax-deductible donations to the NPMS Center **online** by simply going to **Stonybrook.edu/pediatricmsgiving**

We offer memorial and honor donations. Please contact us at 631-444-8096 or 631-444-1454 or email dominique.stanley@stonybrook.edu

MS FACT

Magnetic Resonance Imaging (MRI) provides a picture of the brain and/or spinal cord to evaluate MS activity. Acute inflammation can be detected with gadolinium-enhancement. Research at Stony Brook is advancing MRI techniques to better understand how MS affects the brain.

UPCOMING EVENTS

January 11, 2011

NY Islanders vs. Vancouver Canucks and the National Pediatric Center wins! For more information call 516-351-1799.

January 15, 2011

A one-day Winter Camp in Manhattan open to any MS teen (with parent). For more information call 631-444-3578.

March 17, 2011

MS Awareness Day at Stony Brook University Hospital lobby.

About the MS Centers

There are two MS Centers located within Stony Brook University Medical Center, both designated Centers of Excellence by the National Multiple Sclerosis Society.

The MS Comprehensive Care Center is headed by two internationally recognized experts in MS, Drs. Patricia K. Coyle and Lauren B. Krupp, providing expertise and the latest cutting edge treatment and information to adults with MS.

The National Pediatric MS Center, founded and directed by Dr. Lauren Krupp, is committed to improving the lives of children with MS and advancing a research program that will benefit all people with MS.

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