



# Multiple Sclerosis News

Winter 2011-2012

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

MAY YOU ENJOY  
A JOYOUS  
HOLIDAY SEASON  
AND A HEALTHY  
AND HAPPY  
NEW YEAR!

2012

 STONY BROOK  
UNIVERSITY  
MEDICAL CENTER



## Join Us On Facebook!

Stay Updated on all our events and happenings: "Like" The National Pediatric MS Center.

## ADVANCING RESEARCH: An Update

There has been an explosion in clinical and research work in multiple sclerosis (MS). This year the European Congress for Treatment and Research in Multiple Sclerosis (ECTRIMS), which took place in Amsterdam in October, had the largest number of attendees ever. More than 7500 clinicians and researchers came to the meeting from all over the world; all dedicated to ending MS. The research highlights covered new therapies soon to come to market, studies of new agents in earlier stages of development, and progress in research that could lead to entirely new treatment approaches. Included were progress reports on advances in understanding and treating pediatric MS.

The results of clinical trials confirmed earlier studies that had pointed to new oral treatments. One of the most promising is fumarate (BG12). Findings presented at the meeting was that this pill was associated with close to a 50% reduction in relapse rate relative to placebo, slowed disability accumulation, and had positive effects on brain MRI. Side effects are few. Biogen, the manufacturer, hopes to bring this medication to market in 2012. The safety profile is impressive and the medication has a unique mechanism, modifying cellular metabolism in ways favorable to MS. Another confirmatory clinical trial addressed the role of daclizumab; this medication is given through injection under the skin, but needs to be administered only once a month. The dramatic reduction in relapse rate and disability begins within 2 months of treatment. Interestingly, another medication that was tried in MS and directed against B cell reduction failed to work. Why even mention this? Medication failures can be extremely important in that the results, while disappointing, still inform researchers that previously held models thought to be responsible for MS, need to be revised. They help us from going down the wrong path in drug discovery.

Advances in symptomatic therapy were also reported. Fampridine (Ampyra) which enhances walking speed was shown to benefit treatment responders for 3 or more years, overcoming the concern that this treatment strategy might be short-lived. For treatment of MS relapses in those individuals who fail to respond to steroids, plasmapheresis can help. This form of therapy involves removing from the blood those proteins and inflammatory molecules which are responsible for the transient neurologic dysfunction that occurs during an MS relapse.

Other information served to debunk therapies previously thought to help MS. For example, the supplement Omega 3 did not benefit either an animal model of MS nor individuals with the disease. Somewhat disappointingly, a recent study failed to show a treatment effect with Vitamin D. However, clinicians still believe it is important to maintain high normal levels of vitamin D in the blood. The rationale is that several studies have shown that in adults as well as children with MS, a low level can correspond to a subsequent increase in relapse rate relative to higher levels.

What about progress in the more fundamental causes of MS, particularly why people with the relapsing form of disease over time can transition to a more progressive phase? For people with primary or secondary progressive MS

*please turn to page 2*

## Benefit for Required Minimum Distributions Expires December 31st!

The Federal tax code has been in such flux the past couple of years that it's difficult to keep track of which credits are unchanged, which have expired and which have been renewed.

The Center would like to remind our supporters that, through December 31, 2011 you can still help us and simplify your taxes by making a charitable contribution *directly* from an IRA account. If you (or a family member)

- are over age 70½
- don't need your full Required Minimum Distribution (RMD) from an IRA for living expenses
- normally contribute to qualified non-profits

the IRS will allow you to exclude up to \$100,000 per year of your RMD from your gross income if the distribution goes directly to a qualified charity.

**It's unclear whether this charitable exclusion will be renewed again when it expires at the end of this year, so we hope you'll take advantage of it while you can!**

Please ask your financial advisor for more details regarding the income exclusion or the process for making contributions from your IRA or call us at 631-444-1454.

## Interested in attending the Summer 2012 Teen Adventure Program for adolescents with MS?

Contact Maria Milazzo at 631-444-7802.



## Advancing Research *(continued from page 1)*

the current disease modifying therapies appear not to help as much. New research approaches to the immune system were reviewed that might provide insights on how to prevent this progression as well as help those who are already in this phase of MS. There are two major types of immune response that our bodies use to combat infections. In MS, attention has only been given to one of them, the "adaptive immune response". It is thought that the subpopulation of cells contributing to the adaptive immune response cause MS since instead of attacking just infectious agents which is what the cells are supposed to do, they turn against the myelin covering the neurons in the brain and spinal cord. This adaptive immune response contains CD4 cells, CD8 cells, and cells which regulate the immune response. Current therapies are designed to shift the balance to those cells which downregulate the cell population responsible for the inflammation in the central nervous system that underlies MS. However, there is an entirely different arm of the immune system, known as the innate immune response. The cells involved in innate immune response are entirely different and include monocytes, microglia, and dendritic cells. These cells likely participate in the progressive phase of MS and could be the actual mediators on the final injury that occurs in the central nervous system. The new awareness of the contribution of this arm of the immune response opens up the possibility of entirely new therapeutic approaches, particularly treatments that could help progressive MS.

Finally, as has been true of the past several meetings, new advances are occurring in pediatric MS, some of which our pediatric MS center has contributed to. Data on the important interaction between viral exposures and genetic factors was

highlighted. We, along with researchers from University of California at San Francisco, have found that while the virus EBV is associated with an increased risk of MS, other viruses might be protective. Exposure to the virus CMV appeared protective in that antibodies to the virus were present more often in healthy controls relative to the children with MS. We are also in the midst of an NIH funded project that will further examine the interaction between different environmental exposures that contribute to MS development.

Adult MS research at Stony Brook is also thriving and covers new MS therapies including non-pharmacologic interventions designed to improve cognition and to improve quality of life. At the meeting, in conjunction with an international group of clinical researchers we provided important information on how cognition in MS should be assessed in clinical research and in outpatient practice. The adult MS program is also beginning a treatment study for individuals with progressive MS and for certain eligible individuals with MS studying the potential benefits of a specific meditation program. Individuals interested in hearing more about this and other research programs can contact Pat Melville, NP at 631-444-8164.

More than ever before, there is an increased collaboration across the world among individual researchers trying to end MS. Additionally, more and more academic institutions are working with members from industry to develop new MS treatments. The growing number of researchers combined with the energy of individuals and their families affected by MS, and the generosity of those who can support research to end the disease, are all exciting developments which will get us closer to the cure.

# HAPPENINGS

## Summer Soiree



(l to r) Dr. Lauren Krupp, Dr. Anita Bellman, Founder, Merry Sloane.



(l to r) Lainie Kazan, Michele Lee and Joely Fisher entertained all at the 2011 Summer Soiree.



Congratulations to the Summer Soiree Committee for raising almost \$250,000 at their Summer Soiree by Day luncheon.

## Harvest Sunset Dinner



(l to r) Tom D'Angelis, Leslie Ferrara and Mary McCarthy.



(l to r) Honoree Rosanne Rogé and Dr. Kenneth Kaushansky, Dean of Medicine, Stony Brook University.



(l to r) Ron Rogé, Honoree Rosanne Rogé, Jo Biederman and Dr. Lauren Krupp.

**Believe  
in a world  
free of MS**

Make your tax-deductible donation to the NPMS Center **online** by simply going to **[Stonybrook.edu/pediatricmsgiving](http://Stonybrook.edu/pediatricmsgiving)**

We offer memorial and honor donations. Please contact us at 631-444-1454 or email [dominique.stanley@stonybrook.edu](mailto:dominique.stanley@stonybrook.edu)

---

## SPECIAL THANKS

The National Pediatric MS Center would like to thank all of its donors and supporters in 2011. Your involvement makes it all possible.

A very special thanks to Cynthia Marks, the William Marx Foundation, Merry & Richard Slone, and the Slomo & Cindy Silvian Foundation for their generous support of the Teen Adventure Program and tireless efforts on behalf of the National Pediatric MS Center.

***Would you like to raise money for children with MS? Hold a bake sale, organize a walk, hold a bowling party or get creative and come up with your own idea. We can help YOU make a difference – Call 631-444-1454 to learn how!***

## UPCOMING EVENTS

- 1/14/12 A one-day Winter Camp in Manhattan open to any MS teen and their parents. For more information call 631-444-3578.
- 2/9/12 It's the NY Islanders vs. Montreal Canadians—and the National Pediatric Center wins! For more information call 516-351-1799 or 631-444-1454.
- 3/15/12 MS Awareness Day at Stony Brook University Hospital lobby. All are welcome.

## 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.

MS Comprehensive Care Center 631-444-MSCC (6722)  
National Pediatric MS Center 631-444-7802

Mail: Dept. of Neurology, HSC L12, Room 020,  
Stony Brook, NY 11794-8121

MS Comprehensive Care Center/  
National Pediatric MS Center  
Stony Brook University Medical Center  
Department of Neurology  
HSC L12 Rm 020  
Stony Brook, NY 11794-8121



NON-PROFIT  
US POSTAGE  
PAID  
NEW BRUNSWICK, NJ  
PERMIT #128