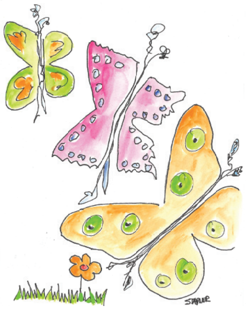
Multiple Sclerosis News

Summer 2011

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

Summer Soirée by Day



Join us for a fabulous afternoon to support MS research!

Featuring entertainment by
Lainie Kazan,
Joely Fisher
and
Michele Lee

The Summer Soiree by Day
Tuesday July 26th, 2011
The Glen Head Country Club
11:30am-2:30 pm

Prizes Galore!

Call (631) 444-1454 for more information

STONY BROOK
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ADVANCING RESEARCH

Since the last newsletter, major developments in the treatment of MS have emerged. Two definitive Phase III major clinical trials are now completed and the results have been presented on two new oral agents, both with excellent findings. Laquinimod, from Teva Neuroscience, is an immune modulating agent with potential neuroprotective properties. A two year study of over 1000 participants showed that laquinimod reduced relapse rate, compared to placebo treated patients, by 23%. Disability accumulated more slowly in the treated group with 36% fewer patients progressing on measures of neurological impairment; the rate of cerebral atrophy was diminished by 33%. Relative to placebo this clear reduction in disability and atrophy in conjunction with only a relatively mild reduction in relapses suggests that neuroprotection could be playing a role in this medication's beneficial effect possibly independent of inflammation.

The other oral medication with equally exciting results is fumarate, made by Biogen Idec. Fumarate, also known as BG-12 was studied in a clinical trial involving approximately 1200 individuals with MS who were randomly assigned to either active drug or placebo and followed over two years. Fumarate reduced relapse rate relative to placebo by 52% and slowed disability progression by 38%. Information about brain atrophy isn't yet available.

While these are major advances for relapsing MS, there still remains a paucity of options for patients with progressive disease. However, a clinical trial is on-going testing fingolimod (Gilenya) in MS and additional studies at Stony Brook for primary progressive MS will include laquinimod and ocrelizumab (a therapy designed to decrease circulating B cells). Another very novel therapy to be tested at Stony Brook involves injection of cells that have a potential to repair damaged tissue in MS. This study will begin in July.

In addition to offering participation in clinical trials designed to modify the disease course, the adult MS center is also testing therapies for improving MS symptoms and quality of life. To address the memory and related problems associated with MS, a computer-based rehabilitation intervention will be tested for its ability to improve cognition. Another non-pharmacologically based program involves meditation, which will be taught to individuals and will be tested for its effects on MS related symptoms. While this initial study is restricted to individuals being treated for their MS with glatiramer acetate (Copaxone); future studies will be open to all individuals with MS. As well as these opportunities to participate in research studies, the adult MS center continues to provide clinical consultations, on-going care, and an educational series about issues relevant to all individuals and families affected by MS.

The pediatric MS center is making great strides in uncovering the pathogenesis of MS. We are beginning a collaborative federally-funded

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Advancing Research *(continued from page 1)*

investigation on the environmental and genetic interactions underlying pediatric MS. Insights gleaned from this work can benefit all individuals with the disease. The study will examine the frequency of exposure to various viruses among children with MS compared to children without MS. A total of 10 pediatric MS centers across the country will enroll participants. Genetic analyses will be carried out to identify markers of MS and to determine whether an interaction between specific viruses and an individual's genetic background is associated with MS risk.

A fair body of knowledge has accumulated regarding the role of Epstein Barr Virus (EBV) exposure and MS risk. Previously the National Pediatric MS Center participated in an international project that showed that children with MS have a greater likelihood of exposure to EBV than do children without MS. Similar findings regarding an association between EBV and MS risk have also been noted in adults. However, published in June of this year were the results of an investigation carried out between the National Pediatric MS Center at Stony Brook and the pediatric MS center in San Francisco, California. We found that exposure to common viruses other than EBV actually appears to lower the risk of MS. This observation is consistent with the "hygiene hypothesis" of MS. This interesting explanation for MS suggests that exposure to infectious agents helps the immune system to avoid the detrimental autoimmune reactions underlying MS. More research is needed to expand our understanding of the association between infections and MS. The NIH study will further address this important research area.

The pediatric MS center continues to provide multidisciplinary care to all children with MS. We provide consultation to pediatric neurologists from New York City including physicians practicing at NYU, Columbia, Cornell, and Westchester. We have seen children with MS who have developed the disease as young as 20 months and up to age 17. Almost all children and families are willing to provide blood samples that are being used for research to better understand why MS develops in children. Assistance from our nurse practitioner, social worker, and child psychiatrist helps families (including those with the youngest affected children) cope in positive ways and enables them to move forward despite the diagnosis. Input from our consultants from ophthalmology and neuroradiology helps provide information relevant to planning treatment and determining prognosis.

Overall, it is clear that our understanding and treatment of pediatric MS has advanced. It is also rewarding to see the progress that has occurred in new drug development. While the ultimate goal of ending MS has not yet been achieved, we are moving steadily closer to that objective.

KEEPING YOUR COOL THIS SUMMER!

Summer is finally here but with it comes the hot, humid weather. It is not uncommon for MS patients to feel the effects of the heat with a temporary flare-up of their symptoms. The recurrence of symptoms is usually short-lived and does not represent permanent damage. The symptoms will generally resolve when core body temperature decreases. There are some strategies that may make it easier for you to keep cool this summer. Many patients benefit from cooling apparel, such as cooling vests, hats, bandanas and wrist bands. These items allow you to participate in outdoor activities while preventing an increase in your body temperature. Going outdoors in the early morning before the heat of the day sets in can also be helpful. Keeping a cold water bottle with you at all times can be beneficial and helps to decrease the risk of dehydration. Staying in air conditioning on days of excessive heat and humidity might be wise. Small battery operated fans can be purchased fairly inexpensively and can also be useful. If you go to the beach make sure that you go into the water frequently to cool off. And don't forget the sunscreen!

The summertime can be a challenging time for people with MS, but you don't need to miss out on the fun. There are a variety of resources available to help you. The MS Foundation has a Cooling Program available for patients with MS. You can get more information from their website: www.msfocus.org. Another resource for information about types of cooling vests available is www.PolarProducts.com.

Have a happy and safe summer!

Dr. Lauren Krupp

ASK THE EXPERT

Q: I hear there is a new oral therapy for MS.

A: Yes, Gilenya (fingolimod) was approved in October 2010. It is a pill that is taken daily. The medication sequesters special types of white blood cells, called lymphocytes, in the lymph nodes. There are evaluations that need to be done before you begin treatment with Gilenya including an eye exam, blood work and an EKG. You should discuss this medication with your health care provider to find out if it is right for you.

"Camp is the Best Time of the Whole Year"

Teen Adventure Program Campers, Summer 2010.

Spring is in the air after a long winter. We hear from our friends in Alaska that the snow is melting even there. With spring, comes plans for the Teen Adventure Program… otherwise affectionately known as our "MS Camp". Announcements have been sent, information is posted to our website, and applications are pouring in from across the country.

Teen Adventure Program (TAP) 2011 serves teens with MS. "I waited 11 months for this week….camp is the best time of the whole year" stated one returning camper as she arrived last summer. Campers are busy challenging themselves in an outdoor environment, trying new activities such as kayaking, sailing, and a high ropes course. A community of affected youth develops as relationships are formed that last long after the kids return home.

This summer, there will be two overlapping sessions, including one for teens who have not attended our program before, and a second session for those who have participated in the past. The campers will be mentored by a group of young adults with MS who are former campers. The mentors share first hand experiences of living successfully with pediatric onset MS.

The Teen Adventure Program is open to all teens with MS (13-18 years of age). The camp is located in Exeter, Rhode Island. Applications and information can be found at www.pediatricmscenter.org.

SPECIAL THANKS

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

A Very Special Thanks to Merry and Richard Slone, Rina Ambrosio, Nancy Rifkind and The Winston Foundation for your generous support and tireless efforts on behalf of The National Pediatric MS Center.

HAPPENINGS

The Ambrosio/Visconti Family at the NY Islander Fundraiser in January 2011.

Two happy campers at winter camp, January 2011.

Dr. Patricia Coyle and Dr. Lauren Krupp on MS Awareness Day at Stonybrook in March 2011.

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

UPCOMING 2011 EVENTS

July 17th – July 23rd — The Teen Adventure Program

July 26th — The 6th annual Summer Soirée by Day fundraiser

September 15th — Patient Education Seminar

October 13th — Patient Education Seminar

November 10th — Patient Education Seminar

November 17th — The 2nd Annual Harvest Sunset fundraiser

December 8th — Patient Education Seminar

MS FACT

Vitamin D may help to prevent relapse frequency in people with MS (as well as provide benefit in other diseases as well). Your physician can help determine the appropriate dose for you.

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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