Pediatric MS

Winter 2008
The National Pediatric MS Center at Stony Brook University Medical Center

SAVE THE DATE

ADVANCES IN PEDIATRIC RESEARCH

**Thursday,
April 2, 2009**

STONY BROOK UNIVERSITY
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CME credits available!

For info or to register, contactJo Biederman 631-444-8096 or johanna.biederman@stonybrook.edu

Wishing you a wonderful holiday season and a New Year of peace and happiness

STONY BROOK
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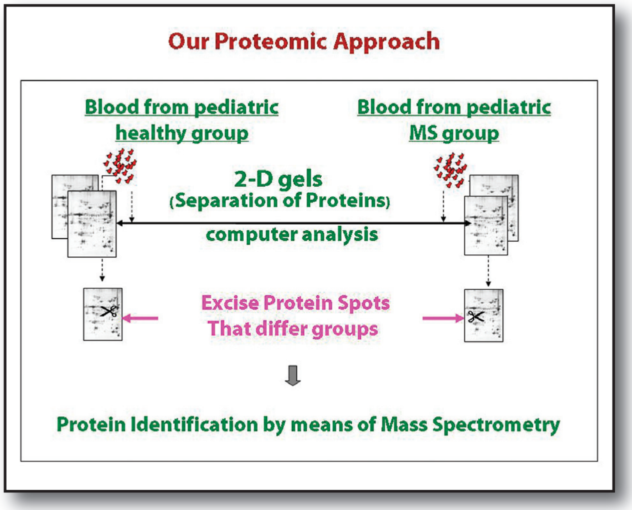
Advances in Research

A number of groundbreaking treatment studies in MS have recently come to light. Results of a multicenter, controlled clinical trial of oral dimethyl fumarate, Biogen Idec, for relapsing remitting MS was recently published in a major medical journal.



This seminal study found that dimethyl fumarate at the highest tested dose caused a 69% reduction in active inflammation compared to placebo. The mechanism of action of this medication is that it affects the immune system in a favorable way and it offers protection against demyelination.

The study involved 257 people and will be followed up with a larger study. The results could be ground breaking if the findings of this preliminary study are confirmed.

Another treatment study recently published in the journal, *Lancet*, showed that a medication administered intravenously had a powerful therapeutic effect. In this clinical trial alemtuzumab, made by Genzyme Corporation, reduced the accumulation of disability and the frequency of relapses in people with early relapsing-remitting MS. Alemtuzumab was compared to Rebif (interferon beta-1a) made by EMD Serono. Those taking alemtuzumab had a 74% reduction in the risk of MS relapse compared to those on Rebif, and a 71% reduction in the risk for sustained accumulation of disability. Given that Rebif is an established and effective MS therapy these are dramatic treatment results.

Unfortunately, those on alemtuzumab, an immune-suppressing monoclonal antibody, experienced adverse events more frequently than those on Rebif. Future studies with alemtuzumab are being planned and will need careful monitoring to avoid the side effects observed in the study.

A number of research studies on children with MS are shedding new insights to the disease. The National Pediatric Multiple Sclerosis Center currently has a manuscript accepted for publication which reports on a novel analytic approach (see figure above) using proteomics, which examines the pattern of protein expression between patients and comparison groups. We had the novel and exciting finding that the levels of 12 proteins were increased in the blood of children with MS compared to healthy children.

Many of these proteins have potential links to the pathogenesis of MS. One of the identified proteins interacts with vitamin D, whose low levels have been associated with MS risk; another protein has been associated with the enzyme metallomatrix proteinase

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The Parents Corner

Eva Rodriguez, O.T.R./L.

Planning your child's needs educationally with school personnel isn't always a simple process. Special education can seem like another world, with a culture so foreign, right down to the vocabulary. There's Section 504, ADA, Tech Rehab Act, and IDEA, acronyms that shorten the need to communicate, but create the atmosphere of a secret club.

Section 504 is a civil rights law that ensures your child has comparable access to the education offered to a child without special needs. This involves reasonable accommodations for your child to access the education being offered to all children.

To ask for these accommodations, contact the school representative (usually the principal or school psychologist) as well as the district office that addresses students with special needs.

It's important to contact both the school representative and the district representative **in writing** so there is an official record.

Key points in using Section 504:

- Section 504 is just for "equalizing the playing field" for your child's educational needs.
- Section 504 accommodations may vary from district to district.
- Early official school documentation is important to prevent misunderstandings, serves as a reference point, and is helpful when your child decides to take the SAT, ACT or both.

Fundraising Update

THANK YOU FOR GIVING HOPE TO TEENS AND CHILDREN WITH MS

Our thanks to the entire **Summer Soiree Committee** for raising almost $190,000 at their fabulous event. Here, Dr. Krupp poses with honoree Anne Dunne, founder Merry Slone and the Committee.

An exciting night at Shea Stadium as the Mets spotlighted a **Night for Pediatric MS.** Maria Milazzo joins Steve Carbone and the Visconti Family.

Photo Credit: Gary Gershoff / Wireimage

We thank Clay Walker (here with Dr. Krupp and Julia Russo) for his $100,000 gift through his **Bands Against MS (BAMS) Foundation** that does such an outstanding job supporting MS causes.

Thanks to Rebecca Kane and Kim Fish for helping to keep us financially healthy by organizing events such as **Making Moves for MS** and a campaign to support the Teen Adventure Camp. **Thanks to all!**

Teen Adventure Camp A VOLUNTEER'S PERSPECTIVE

Kim Fish, an accomplished professional young woman, volunteered at our Teen Adventure Camp Program this summer. Here are her thoughts:

> “Thank you so much for bringing the magic of this camp to life.”

For many of us, camp was the most special place on earth. It was the place where we made some of our greatest friends, learned how to work together with our peers and learned to be friends with people who may not be exactly like us. It was the place where memories were created and amazing friendships were formed. It was a place where you could just be yourself!

This summer I had the unbelievable opportunity to return to camp, but this camp was different. Created for teenagers who have been diagnosed with Multiple Sclerosis, it is run through the Stony Brook National Pediatric MS Center. For many of the teens, this camp is the only time and place they see people like themselves.

Upon meeting the teens at the train station I knew this would be unlike any experience I had ever had! From the ropes course where we learned to work together, how to ask for help where we needed it, as well as to see how we can overcome obstacles, to the group discussions where people shared social challenges they have faced, each program motivated me more and more.

Kimberlee Fish (C) shares a hip moment with this summer's Teen Adventure Campers

These amazing young people showed me their time together literally has saved their lives. One camper said it got him out of a deep depression; another called it the only place where he feels he can participate in activities and, for all of them it is the only time each year where they completely fit in, regardless of how they are feeling at any moment.

To help a child experience this extraordinary camp, please see the response coupon on last page. Thank you for your support!

Spotlight on Staff: MARIA MILAZZO, NURSE PRACTITIONER

Maria has worked in Neurology at Stony Brook for 15 years. She was one of the first to make the connection that kids get MS too! In 2002, she assisted Dr. Lauren Krupp in opening the first pediatric MS Center exclusively dedicated to treat children and adolescents with MS.

Maria is usually the first contact families have with our Center. She is a tremendous help in supporting the kids and their families as they wind their way through the health care system here at Stony Brook.

She is the “go to” person for almost everything – information about MS, education for both families and the medical community, coordinating care and most importantly providing much needed comfort and support to both the kids and their families.

Her calm, pleasing manner does much to help alleviate the fear and apprehension of living with a chronic disease.

Maria is available to answer your questions. Please call her at 631-444-7802.

Research

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which breaks down the blood brain barrier and facilitates the influx of activated T cells into the central nervous system. The identification of patterns of protein expression in MS patients has the potential of improving our understanding of MS and could also provide a non-invasive diagnostic tool that might supplant the use of the more invasive lumbar puncture.

Other research that shows promise is focused on mechanisms related to recovery and repair. The National Pediatric MS Center has had a long interest in research related to neuroprogenitor cell function and repair in the brain of individuals with MS. Our on-going research has been directed at finding non-invasive ways of imaging those cells that repair the damage to myelin producing cells.

Now, other researchers are examining ways in which in MS the repair potential of these neuroprogenitor cells are inhibited in animal models of MS. Several studies have indicated that, early in the disease, immature myelin-making cells called "oligodendrocyte progenitors" are recruited to generate new myelin. A sufficient number of these cells is needed so that progenitors can migrate to the site of myelin damage and develop into myelin-making cells. Then, genes that instruct the formation of myelin components are activated and myelin is formed. In MS, this process fails. A researcher, Dr. Casaccia is studying whether some molecules may inhibit the activation of the genes that help myelin formation.

Casaccia's team observed the gene activity during oligodendrocyte development in mice with damaged myelin and found that certain enzymes are crucial to this process but appear deleted in the animal models. Restoring their function might lead to a process of recovery and repair of the damage which occurs to the myelin in MS.

Overall, while people continue to struggle with MS, and new individuals continue to be diagnosed, there is steady progress in our understanding of the disease. New insights into strategies for neuroprotection and repair are taking place.

Even more importantly, there are better therapies being developed that are easier to administer or more effective or both. The future for people with MS is increasingly hopeful.

About the National Pediatric MS Center

The National Pediatric MS Center is a unique multidisciplinary clinical and research program located within Stony Brook University Medical Center, one of the world's leading research institutions. The Center was the first of its kind in the United States exclusively committed to the care of children and adolescents with MS. It is a designated ***Center of Excellence*** *by the National Multiple Sclerosis Society.*

Our mission: *We are committed to improving the lives of children with multiple sclerosis and advancing a research program that will benefit all individuals with MS.*

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THANK YOU

MEMORIALS & HONORS

Please remember the Pediatric MS Center when you want to send a memorial or honor a loved one on a birthday or anniversary.

Simply contact Jo Biederman at (631) 444.8096 and she will notify your friends or family of your thoughtfulness along with your personal message.

Donations can be made by credit card

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