

Multiple Sclerosis News



Stony Brook Children's

LOURIE CENTER FOR PEDIATRIC MS

Summer Soirée by Day

Join us for a fabulous afternoon
to support MS research!

Featuring Comedian
Wendy Liebman

Thursday, July 25
Old Westbury Golf & Country Club
11:30 am - 2:30 pm

Call 631-444-1454 for details



Stony Brook
Medicine



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Center for Pediatric MS.

Improving Cognition in Individuals with MS

Since the late 1870's, neurologists have noted that MS symptoms can include problems with memory and slowed information processing. It is estimated that between 40 – 60% of people with MS have cognitive problems. Fortunately, for most, these problems are only in the mild-to-moderate range. However, despite the recognition of the potential for cognitive problems, there is still no reliably effective treatment.

Disease-modifying medications such as the interferons, glatiramer acetate, or the newer medications may slow the progression of deficits, but do not restore function. Treatments aimed at improving symptoms have shown mixed results. For example, at Stony Brook, we have completed studies with the medication Aricept to improve memory in people with MS. While our initial trial was positive, these findings were not confirmed with our larger multi-center study.

Recently, studies have demonstrated that stimulant medications may have some promise. These medications, typically used to treat Attention Deficit Hyperactivity Disorder (ADHD), have been shown to enhance cognitive performance in a wide range of conditions. In one study, individuals with MS treated with stimulant medication showed improvements in memory but not on measures of processing speed. A re-analysis revealed larger gains in memory in those with more pronounced impairment. Another study showed that those receiving a stimulant medication improved significantly on a measure of processing speed. The treated patients

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A Message from Clay Walker

Most of you know me as a country music artist and many of you have attended my shows. I have actually met many of you face to face or have received your emails and letters. I travel often both performing and for MS education and outreach. What you may not know is this: I was diagnosed with multiple sclerosis in 1996 when I had just completed my fourth album and already had five No. 1 hits. I was on top of the world. At the time of my diagnosis not much was known about the disease and the future looked bleak. If you had asked me when I was diagnosed, that very first day, if I would still be alive today, honestly the response would have been "no." I am happy to say that was 17 years ago!



Clay Walker, Dr. Lauren Krupp and young friend.

After coming to terms with the news, I steadied myself and regained my fighting spirit. No matter what I have had to face in life, I try to do it with a positive attitude. When hit with things in life that we cannot control, it is important to remember the one thing we can control—our own attitude.

Stay Strong!
Clay Walker

Stony Brook Children's To Build Ronald McDonald Family Room

Stony Brook Long Island Children's Hospital is partnering with The Ronald McDonald House of Long Island to develop a Ronald McDonald Family Room Program to provide support for families of children who are hospitalized each year at Suffolk County's only children's hospital.

The Family Room, opening in August 2013, will be located in the inpatient Pediatric Unit of Stony Brook University Hospital and will serve parents of more than 7,000 children ages 21 and younger who are admitted to the hospital each year. Plans for the space include a living, kitchen and dining area, private bathroom, laundry facilities, transportation services, meal program, computer access, storage space and complimentary beverage service for families.

This area will provide a valuable place of respite for parents and siblings of our patients during a difficult time in their lives – with the same hospitality and compassion that Ronald McDonald Houses are known for worldwide.

Improving Cognition in Individuals with MS *(cont'd from page 1)*

also showed significant improvement on the study's measure of verbal learning but not on the measure of visual learning. While these initial results are promising for MS patients, there is limited potential for long-term stimulant use. First, there is the risk for abuse and dependence associated with all stimulant use. Second, tolerance is often reached and long-term benefits tend to taper or even reverse. Therefore, even if safely tolerated, long-term stimulant use may not provide sustained cognitive benefit.

Looking to non-pharmacological approaches, recent technological advances have led to the potential of computer-based cognitive exercises to lead to meaningful improvements in function. Cognitive remediation (also referred to as cognitive rehabilitation or cognitive training) works to restore functional abilities. Several studies have demonstrated that cognitive remediation can be effective in MS and in a range of other conditions associated with cognitive impairment. Areas of improvement have included processing speed and memory functioning, the cognitive functions most often affected in MS. However, cognitive remediation has typically required administration by a clinician with numerous clinic visits. The recent advance to provide these remediation exercises through an internet-connected computer offers significant advantages, such as more rapid presentation of individually-tailored exercises and the option of delivery at home and at the patient's convenience. Computer-based cognitive remediation programs have been demonstrated to be effective in a range of patient groups with cognitive impairment such as mild cognitive impairment, traumatic brain injury and schizophrenia. A recent review indicated that computer-based cognitive exercises are more effective than any medication and are the most promising option for the prevention of cognitive decline in older adults.

There are other steps that people can take to help with their cognitive function. Studies have shown that complex speeded cognitive tasks can be affected by fatigue. Since most people with MS experience fatigue that worsens as the day progresses, it can be helpful to plan activities that are mentally demanding in the morning hours or after a period of rest. As memory can be affected by MS, using memory aides can also be helpful. These include using one's phone, Ipad, or a note pad. It is important for individuals to remain calm when trying to remember something such as a name or place. It is very easy to become frustrated but, getting angry or stressed can further impede recall. Compared to those without MS, the retrieval process might take longer. So, the message is to take your time, try not to get stressed, and often the solution will arrive.

We believe that the future holds great promise with research showing new ways to ease the burden of cognitive difficulty experienced by some with MS.

Clinical trial starting at Stony Brook

With a grant from the National MS Society, we will be able to directly study the effects of cognitive exercises in MS. We will be comparing two approaches to computer-based exercise. To participate, patients must be between the ages of 18-70 and have at least mild difficulty with cognitive functioning as measured on a brief screening test (the SDMT). Individuals with any of the MS subtypes (relapsing, primary progressive, secondary progressive, or progressive relapsing) are eligible. Participants will be given a laptop computer to take home for the 12-week study. Exercises should be completed approximately one hour per day, five days per week. All participants will be paid.

If you or someone you know is interested in participating in this Computerized Cognitive Exercise please contact Maria Amella at 631-444-7993.

Celebrate 10 Years of Pediatric MS Care and Research

Make your tax-deductible donation to the Lourie Center for Pediatric MS **online** by simply going to Stonybrook.edu/pediatricmsgiving

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

HAPPENINGS

Harvest Sunset Dinner

November 2012

The Harvest Sunset Dinner honored Lisa & Robert Lourie for their outstanding philanthropic commitment to multiple sclerosis research. Their support of the pediatric MS program and the new Lisa and Robert Lourie Imaging Suite will greatly impact the patients served at Stony Brook Medicine. It was an extraordinary night which raised more than \$120,000.

Join us at this year's event on November 21!



Event Emcee News 12's Shari Einhorn and Leslie Ferrara



L to R: Dr. Sam Stanley; Dr. Lauren Krupp; Dr. Robert Lourie; Mrs. Lisa Lourie; Dr. Ken Kaushansky

Teen Adventure Program ★ 10th Anniversary ★

This July we will celebrate the 10th summer of the Teen Adventure Program. All of us at the Lourie Center are truly looking forward to commemorating 10 years of fun and memories made at MS camp. We are extremely grateful to all those who make this camp program possible each year. Whether it be through the generous donation of time, talent or financial support, we thank you. It has been a joy for us to see the campers grow along with the camp program. Our inaugural year brought a scant eight campers together with five staff. Currently we serve more than 40 campers and eight mentors (former campers that now serve as mentors to the campers). Our newest staff member is a former camper who comes to us with his years of experience and enthusiasm for the Teen Adventure Program!

Many fun activities are planned to celebrate our anniversary, including an Open House for all those who have been involved

with our program over the years including campers, volunteers and staff. We look forward to many good laughs as we share memories.

Registration is currently open and once again we have a great response from young people across the country. We look forward to meeting the new campers and re-uniting with returning ones. As we have in years past we will all meet in Rhode Island. Activities include kayaking, climbing at a rock gym, sailing in Newport Harbor, swimming, yoga and a group creative art experience. Something new: this year a nutritionist will host a program on healthy living. As always, there will be plenty of opportunity to share, both formally and informally with peers, about life with MS.

Contact us with questions about camp at 631-444-7992 or www.pediatricmscenter.org.



Upcoming 2013 Events

July 25 – Summer Soirée by Day luncheon fundraiser
Old Westbury Golf & Country Club, Old Westbury, NY

August 18 – Pediatric MS Patient & Family Celebration
Spy Coast Farm, Setauket, NY

September 12 – Pediatric MS informational teleconference
Call 631-444-7832 to register

September 19 – Patient Education Seminar, Setauket, NY

October 17 – Patient Education Seminar, Setauket, NY

October 24 – Adult MS informational teleconference
Call 631-444-7832 to register

November 14 – Patient Education Seminar, Setauket, NY

November 21 – Harvest Sunset fundraiser

December 5 – Patient Education Seminar, Setauket, NY

Call 631-444-1454 for details on any of the above fundraisers, celebrations or programs

Did you know there are opportunities to participate in several studies?

There are ongoing opportunities, including cognitive testing, for paid participation in studies to characterize MS. Call Maria Amella at 631-444-7993 for details.

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!

About the MS Centers

There are two MS centers located within Stony Brook Medicine, 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 Lourie Center for Pediatric MS, 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 631-444-6722
Lourie Center for Pediatric MS 631-444-7802

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