

**Our mission** is to find the cause and ultimate cure for multiple sclerosis by funding scientific research grants through The Nancy Davis Center Without Walls program, a nationwide collaboration of the top seven MS research centers in the United States. We will win the Race to Erase MS!

# Vol. 7 Issue 1

# In This Issue

Annual MS Roundtable Summary...Page 3

Photo Gallery: Dance to Erase MS...Page 4-5, Page 12-13

Center Without Walls: Medical Center Summaries...Page 6

Center Without Walls: Collaborative Studies...Page 8

Center Without Walls: Single-Pilot Studies...Page 9

Rituxan Update...Page 7

Stem Cells and MS...Page 7

Center Without Walls: Clinical Trial Summary...Page 8

Health Tip and Resources...Page 10

Brain Exercise: Crossword Puzzle...Page 14

MS Gene Uncovered...Page 15

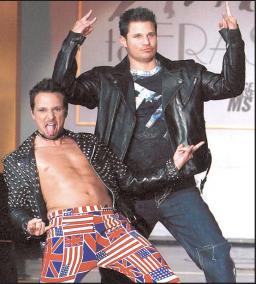
# **Contact Us**

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# Dance to Erase MS April 13, 2007





Ken Rickel, Dee Ocleppo, Tommy Hilfiger, Nancy Davis and Lynn Palmer



Drew and Nick Lachey model in Tommy Hilfiger Fashion Show

Philip Bailey, Verdine White, David Foster and Ralph Johnson

Everyone was dancing in the aisles as Co-Chairs Nancy Davis and Tommy Hilfiger celebrated another successful event with special celebrity presenters Joey Fatone, Drew Lachey, Dr. Phil and Robin McGraw, Ray Romano, Daisy Fuentes, Jon Lovitz at the 14th Annual Race to Erase MS event, themed "Dance to Erase MS".

The event took place on Friday, April 13th at the Hyatt Regency Century Plaza and raised over 2.5 million dollars for multiple sclerosis research thanks to a most generous group of supporters. Tommy Hilfiger Corporation, Associated Television International, American Airlines, EMD Serono and the Hyatt Regency Century Plaza all contributed to the tremendous amount of funds raised to support MS research.

The highlight of the evening included an exclusive celebrity fashion show featuring one-of-akind inspired designs by Tommy Hilfiger modeled by such celebrities as Nicole Richie, Nicky Hilton, Nick and Drew Lachey and Keisha Whitaker. The amazing dancers from "Dancing with the Stars" kicked off the evening with spectacular live performances by musical legends Goo Goo Dolls, Donna Summer and Earth, Wind & Fire who rocked the house and had everyone dancing in the aisles. The show was produced by Associated Television International, Executive Producer Suzanne de Passe, with David Foster as the Musical Director.

The ballroom was bejeweled with an art deco touch by well known designer, Mindy Weiss and extraordinary floral arrangements were generously donated by Marks Garden. Thank you to sponsors Makers Mark, Fiji Water, Wolf Blass Wine, Sapporo and Pierre Marcolini Chocolatier as well as Frederic Fekkai and MAC who created the amazing hair and makeup for the fashion show. (RACE continued on Page 11)

## Message from Nancy Davis President and Founder



"A diagnosis of any life altering disease is a terrifying experience...the world as you know it is changed in a heartbeat. When I was told I had multiple sclerosis fifteen years ago, hopelessness set in as doctors had no substantial information to give me and there were no drugs or therapies available. It is remarkable how the MS landscape has significantly changed in the past fifteen years to help stop the progression of this disease. Miraculously, there are now six drugs with FDA approval and a seventh new drug that will hopefully be

approved by the end of this year. A cure is so much closer than I could have ever imagined. Hopelessness has been replaced by hopefulness.

Through our Center Without Walls program, there are so many more exciting and promising new therapies on the horizon. Our seven centers that make up the prestigious consortium of the Center Without Walls program have made revolutionary discoveries just this past year which you can read about in our newsletter. This expansion of minds working as a team towards a cure gives me confidence that we will win this RACE to Erase MS in the next decade. I am so grateful for the diligent work of our Center Without Walls physicians and the continued support of the many generous and caring contributors to this cause."

Hanup Dains

# **Symptoms of Multiple Sclerosis**

Multiple sclerosis causes a large variety of symptoms.

The most common symptoms are:

- NUMBNESS OR TINGLING
- UNUSUAL FATIGUE, WEAKNESS AND EXHAUSTION
- VISION PROBLEMS
- LOSS OF MEMORY
- POOR COORDINATION OR DIFFICULTY WALKING
- BLADDER PROBLEMS
- SLURRED SPEECH

No two persons with MS will necessarily display the same symptoms, making it difficult to predict the course of the disease for an individual patient.

Symptoms may occur suddenly and remain constant, or may continue in a progressive or episodic pattern. The uncertainty and unpredictability of MS makes living very difficult for the victims, their families and their friends.

An MRI is the most definitive test to properly diagnose multiple sclerosis.

#### The RACE to Erase MS, The Nancy Davis Foundation for Multiple Sclerosis

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# MS Roundtable Forum April 14, 2007

Once a year The Nancy Davis Foundation invites the general public, MS patients, families and friends to attend an MS Roundtable, an open forum in which the distinguished doctors from the Center Without Walls program share advances in ground breaking research. Attendees have the unique opportunity to ask questions and to speak to top research scientists. This MS Roundtable is a significant component to the mission of the Nancy Davis Foundation, and truly is an important compliment to the previous nights fundraising event.

Panel members included Dr. Jeffrey Cohen, Dr. Stephen Hauser, Dr. Adam Kaplan, Dr. Emmanuelle Waubant, Dr. Stephen Waxman, Dr. Howard Weiner and Dr. Leslie Weiner, as well as distinguished guests Nancy Davis, Attorney Mark Barondess, and Claudia Curry Hill. The MS Roundtable highlights important medical research conducted by each of the seven centers, who communicate every month to share their findings, and reinforces the need for the existence of The Center Without Walls program. Dr. Stephen Hauser discussed the importance of the Centers and believes that "They are not only research centers but large busy centers where patient care happens every day....so it truly is a Center Without Walls where we are moving every day from the bedside to the bench."

We would like to thank our sponsors Genentech, Hyatt Regency Century Plaza, Le Pain Quotidien and Fiji Water for their invaluable donations towards this very important educational opportunity which is always free and open to the public. If you were unable to attend our symposium but would like a copy of the program on DVD, please contact (310) 440-4842.





Nikki Levy, Lyndi Hirsch, Carol Hunstman and Michael Utz Nancy Davis with Aj and Katie Brass

Claudia Curry Hill



Dr. Emmanuelle Waubant, Dr. Ari Green, Dr. Bruce Trapp, Dr. Stephen Hauser, Nancy Davis, Claudia Curry Hill, Dr. Adam Kaplin, Dr. Leslie Weiner, Dr. Peter Calabresi, Dr. StephenWaxman, Mark Barondess, Lynn Palmer and Dr. Dennis Bourdette



Nancy Davis and Sarah Small



Dr. Leslie Weiner speaking with Kaley Zeitouni



Dr. Stephen Hauser, Nancy Davis,

Elaine Hauser and Lynn Palmer

Mr. & Mrs. Dean Singleton

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### photo gallery

# **DANCE TO ERASE MS**



Robin and Dr. Phil McGraw, Jan Miller and Jeff Rich



Tommy Hilfiger and Nancy Davis



Tommy Hilfiger Fashion Show Finale



Virginia Madsen

# April 13, 2007



Drew and Nick Lachey



Donna Summer



Katie Brass and Friends



Nicky Hilton and Nicole Richie



David Horowitz and Nancy Davis



Barbara Davis with Ghada Irani and Friend



Nancy Davis with John Rzeznik, Mike Manlin and Robby Takac



Cheryl Burke

and Louis Van Amstel



Earth Wind & Fire and Family



Laura and David McKenzie



Jason and Nancy Davis



Nancy Davis, Lynn Palmer and Brenda Richie









Julia and Alex Davis





Brandon and Nancy Davis



Dee Ocleppo and Tommy Hilfiger



Tara Reid



Anna, Ray and Ally Romano



Nancy Davis, Jennifer Lustig, Lynn Palmer, Debbie Lustig

#### **FALL 2007**

#### PAGE 5



Maria Bell, Tawny, Jerry and Paris Sanders and Laura Baumgarten



Nancy Davis and Ken Rickel



Joey Fatone and Jennifer Tilly



Nancy Davis, Arda Yemenidjian, Veronica Caudillo, Geraldine Tevrizian and Alex Yemenidjian



Tom Arnold and Nancy Davis



John Rzeznick of the Goo Goo Dolls



Bryan Carter with Friends



Dana and Nancy Davis



Barbara and Nancy Davis with Debbie Pattillo



Siran Manoukian, Nancy Davis with Tamar and Bob Manoukian



Teri Garr



Nancy Davis and Lyndi Hirsch



Deb MacMillan and Friends



Paul and Lynn Palmer



Tommy Hilfiger and Donovan Leitch



Andy and Kim Hilfiger with Ken Rickel



Lisa Edelstein



Guest with Henry Fong and Mary Virginia Knight



Lara Flynn Boyle and Donald Ray Thomas



lan Ziering and Nancy Davis



Dolores Robinson, Holly Robinson-Peete and Rodney Peete



Yolanda Hadid, David Foster, and Lyndie Gorlick



Jimmy and Debbie Lustig



Sherry Corday (end right) with Friends

# The Center Without Walls Program Medical Research Update

The Nancy Davis Center Without Walls consists of seven of the top MS centers with complementary expertise in multiple sclerosis research. The NDCWW exchanges scientific information and collaborates at multiple levels. Many scientific achievements in the past year have continued to fuel the NDCWW's commitment to find a cure for MS. Scientific meetings provide an open forum for discussion and presentation of novel ideas and findings. Centers with specific expertise provide valuable support to others, each having a unique background and this constant exchange process is nurturing outstandingly rich research activity. During these meetings, 30 key investigators of the 7 institutions shared information prior to publication. The specific scientific accomplishments of individual Centers are contained in the individual reports. The highlights are presented below:

## **Cleveland Clinic**,

Director, Richard Rudick, M.D.



The Mellen Center has found that some immune communicating molecules called chemokines are key in brain inflammation but also in repair processes. Identifying

which of the chemokine receptors should be targeted will result in the development of novel treatments. The team at the Mellen Center has also reported that nerve cells are transected not only in MS lesions but also in the outmost layer of the brain, called cortex. The team has identified resident immune cells of the brain that play an important role in protecting the brain from injury.

## Harvard Brigham and Women's Hospital,

Director, Howard Weiner, M.D.



The team at Harvard is analyzing the linkage of certain blood and MRI markers with MS activity and response to MS drugs. The team has also combined MRI measures

of disease severity for predicting disease progression in patients with MS. In addition to developing new blood test for MS, the team is investigating the role of neural stem cells during brain inflammation, so deleterious processes can be identified and inhibited in MS.

## **Johns Hopkins**

Directors, Peter Calabresi, M.D. and John Griffin, M.D.



Permanent disability in MS is thought to occur because of irreversible damage to the nerve "wires" called axons. The team at Johns Hopkins is

working towards understanding how nerves degenerate and have developed novel ways to visualize axons and myelin with magnetic resonance imaging. Using

animal models of MS, the team has found that loss of MAG, the innermost part of the myelin sheath, results in increased nerve damage. By understanding how myelin proteins normally protect nerves, they may be able to develop new neuroprotective therapies.

## Oregon Health Sciences University

Director, Dennis Bourdette, M.D.



In the past year, the team at OHSU has discovered that vaccination with part of the receptor located on immune cells called T cells can boost protective white blood cells. This initiating a clinical triplin

has resulted in initiating a clinical trial in MS. The team has also engineered a protein called RTC1000 that can "stun" disease causing white blood cells in MS. Finally they have discovered that blocking a specific protein, called cyclophilin D, in mitochondria, the energy "factories" in cells, may contribute to protecting nerve cells. They will begin testing the ability of a drug that blocks cyclophilin D to prevent nerve damage in the mouse model of MS.

## University of California, San Francisco

Director, Stephen Hauser, M.D.



The main goal of UCSF team is to unravel the genetic makeup that convey susceptibility to MS and dictate the severity of the disease. Multiple collaborations within the

Center Without Walls (OHSU and Johns Hopkins) allow for outstanding recruitment of patient samples from various populations with various risks to develop MS. The team has observed a higher than expected co-occurrence of other autoimmune disorders, both in the individual affected by MS and their relatives. Our new exciting finding that a functional variant of the interleukine-7 receptor is a risk allele for MS highlights the need for large cohorts and justifies a sense of optimism that the genetic approach will be increasingly productive with the new generation of tools now available. USCF has also been part of a team, led by an international consortium of clinical scientists and genomics experts, that have incorporated the two largest collections of MS genetic information worldwide and is the first comprehensive study to investigate the overall genetic basis of MS. Two new large-scale genomic studies have honed in on the main genetic pathway associated with multiple sclerosis (MS), while also uncovering new genetic variations in the disease and suggesting a possible link between MS and other autoimmune diseases.

## University of Southern California, Los Angeles

Director, Leslie P. Weiner, M.D.



The team at USC Center is evaluating the role stem cells may play in brain repair and regeneration. The team at USC has studied differentiation biomarkers that control how

stem cells will develop into various brain cell types that could be used for repair. The team also studies brain cell injury utilizing micro chambers in which they cultivate single brain cells exposed to various immune factors or growth factors. Finally the team is studying viruses as potential MS triggers.

## Yale University

Director, Stephen Waxman, M.D.



The goal of the team at the Yale Center is to restore and protect neurological function in animal models of MS and translate such discoveries toward effective treatments for people

with MS. Key objectives are to investigate the potential of cell-based approaches in the repair of central myelin damage and in the restoration of nerve impulse conduction in MS; to preserve neurological function in the injured brain and spinal cord via novel strategies that protect axons so that they do not degenerate; to study the molecular makeup associated with poor nerve impulse conduction in MS, and identify strategies that will restore normal conduction within demyelinated axons.

# Rituximab (Rituxan) Update Courtsey of UCSF

Rituximab, a drug approved for non-Hodgkin lymphoma since 1997 and rheumatoid arthritis since 2006, is being evaluated as a new treatment for MS.

It targets specifically B cells, the cells making antibodies that provide some of the long term immune protection from infections. Under pathological conditions, B cells appear to also promote inflammatory reactions in several autoimmune disorders including MS.

Rituximab that belongs to the drug family called "monoclonal antibodies" was used in a trial of 104 patients with relapsing remitting MS, most of whom had failed interferon or copaxone. Patients were randomized to receive two infusions of rituximab or placebo (an inactive compound) 2 weeks apart and were followed for one year with regular brain MRI scans, blood tests and clinical evaluations.

Twenty four weeks after treatment was administered, the number of new brain MS lesions was dramatically reduced compared to placebo (90% reduction). The MRI effect seems to occur rapidly, e.g. within the first month or two after treatment, and be maintained for up to 48 months.

In addition, patients who received rituximab had a two-fold reduction of their risk to develop an MS relapse compared to placebo. Overall, rituximab was safe. Main side effects consisted in infusion related symptoms (e.g. symptoms that occur during the infusion or within 24h of an infusion). These side effects include chills, fever, headaches, and transient blood pressure drop, and are usually mild or moderate in severity when using a preventative treatment such as Tylenol and benedryl. These symptoms mostly occur with the first infusion.

Because of these dramatic results, the company making the drug, Genentech, will move forward with two large international pivotal trials that will help confirm efficacy and safety of rituximab before going to the FDA for approval.

Finally, another study with rituximab is almost completed in a large group of patients with primary progressive MS, a form of MS for which there is currently no approved therapy. The results of this study are expected for the end of 2007.

## Stem Cells and MS Dr. Leslie Weiner, USC

The Nancy Davis group at USC has been studying neural stem cells and oligodendrocytes precursor cells derived from stem cells. The purpose is to characterize cells that will eventually be prototypes for transplantation into the brain and spinal cord of selected MS patients.

One important finding is the expression in human cells of a key gene for myelin formation. This gene is myelin transcription factor (MyT1). When it is expressed the myelin precursor cells will continue to divide and will not differentiate into a myelin forming cell. When expression is decreased the cells will begin to produce

myelin proteins. We have found that certain chemokines and other inflammatory molecules will increase MyT1 and could play a role in preventing repair in MS by keeping cells from going on to form myelin. There are many precursor cells in the MS patients' brain, but there is failure to remyelinate for the most part. These same cells do express high levels of MyT1 in MS patients' brain. We are currently trying to engineer human stem cells to modulate the expression of this important factor. We hope that manipulation will promote myelin repair at the time cells are transplanted into the human nervous system.

# **The Center Without Walls:** Group Overview of Clinical Trial Projects

## COLLABORATIVE STUDIES

The Center Without Walls has several collaborative studies under way in various stages of development.

#### **Studies Completed In Past Year**

#### Oral interferon tau:

Twenty eight patients with relapsing remitting MS or clinically isolated syndromes suggestive of early MS have participated in this study at four of the Centers (Harvard, OHSU, USC and UCSF). Oral interferon tau taken during nine months has been well tolerated. Jeff Cohen at the Cleveland Clinic served on the Data and Safety Monitoring Board. Preliminary analysis suggests that oral interferon tau decreases MS activity on serial brain MRI scans by approximately 60%. Final analysis will be provided for the third quarter of 2007. A randomized phase II study is expected to start within the next few months. Oral interferon may turn out to be comparable to approved interferon beta with fewer side effects, and it is easier to administer.

#### <u>Treatment that decreases B cells and</u> antibodies against the nervous system:

All seven Centers have been involved in a new treatment strategy using rituximab, a monoclonal antibody against the B cell marker CD20 that depletes B cells for over six months after the first course of treatment. B cells are believed to participate to MS brain inflammation and make antibodies against constituents of the brain. The results of the randomized, placebo controlled phase II trial establishes for the first time the role of B cells as key players during MS inflammation in 104 patients with relapsing remitting MS (Protocol Chairs: Drs Stephen Hauser and Emmanuelle Waubant, UCSF). Depleting B cells with one course of rituximab decreases disease activity on serial brain MRI scans by 90% and lessens relapses by over 50%

compared to placebo. These exciting results were presented at the American Academy of Neurology in Boston in May by Dr Hauser. Rituximab is administered intravenously every six months. It is FDA approved for non-Hodgkin lymphoma and rheumatoid arthritis, and is well tolerated except for mild to moderate infusion-related reactions. The small phase I study of re-treatment with rituximab confirms safety in 26 patients, and shows that the benefit of rituximab is maintained until the end of the first year of therapy upon re-treatment. These very encouraging results will be confirmed in a large phase III trial expected to start in 2008 that will hopefully lead to FDAapproval of this drug for patients who have relapsing forms of MS.

# Add-on therapy for patients doing poorly on interferon therapy:

This study, headed by the Cleveland MS center and sponsored by Biogen Idec, is the first large pivotal study of combination therapy. Dr. Calabresi at Johns Hopkins participated to the Data and Safety Monitoring Board for this study. Six of the Centers (Cleveland, UCSF, USC, Yale, Johns Hopkins and OHSU) have participated in this trial that compared the benefits of adding monthly Solumedrol or oral methotrexate to Avonex in patients who experienced exacerbations while on Avonex. The results of this study were presented at the American Academy of Neurology in Boston in May by Dr. Cohen from the Cleveland Clinic. The study shows that patients who received IV Solumedrol pulses in addition to Avonex, or Avonex and methotrexate tended to develop less new lesions on the follow-up brain MRI scan at one year compared to patients who received Avonex only, or Avonex and methotrexate. This has direct implications for the treatment of patients who respond incompletely to Avonex as physicians may now stop adding oral methotrexate to Avonex, and will instead prefer to combine Avonex to IV

Solumedrol pulses.

#### **Ongoing Studies**

The NDCWW has continued or initiated patient enrollment in several collaborative clinical trials of oral medications for MS that have been designed by the NDCWW:

- Lipitor in early MS

- Memantine for cognitive impairment in MS

The Center has also continued the collaborative study of a novel intravenous drug, rituximab, in primary progressive MS.

#### <u>Lipitor (atorvastin) for patients with</u> <u>early multiple sclerosis:</u>

Seventy four patients have been enrolled nationwide in this study. We are planning to enroll 152 patients with their very first MS event and monitor for one year the effect of Lipitor compared to placebo. With this study, 6 of the Centers (UCSF, Cleveland, USC, Yale, OHSU and Johns Hopkins) are following up on the exciting work in animal models suggesting that Lipitor significantly decreases the activation of the immune system that occurs in MS. Since Lipitor may also have neuroprotective properties, the centers use spectroscopy, a sophisticated magnetic resonance technique, to determine whether Lipitor prevents brain damage. This is an exciting trial, as the medication is given orally and is much safer than many immunologic therapies considered for MS. This is also one of the first times the CWW centers are able to share their advanced magnetic resonance technology. The study designed by UCSF is sponsored by the Immune Tolerance Network, Biogen Idec and Pfizer.

#### Memantine for MS cognitive impairment:

This year OHSU, in collaboration with USC, has conducted a double blind

#### **FALL 2007**

placebo-controlled pilot trial of memantine for cognitive impairment in MS. Memantine is a glutamate receptor antagonist that has been shown to improve cognition in Alzheimer's disease. This trial is designed to assess whether memantine will improve cognition among MS patients. Eighty patients have already been enrolled in the study.

# <u>Treatment that decreases B cells and antibodies:</u>

The large double blind trial that will evaluate the efficacy of rituximab in patients with primary progressive MS over two years (Protocol Chairs: Kathleen Hawker, Cincinnati and Jack Antel, Montreal) is almost completed. Over 400 patients are participating. We anticipate the results to be available by early 2008. If this study is positive, rituximab could become the first therapy for primary progressive MS. Genentech, the study sponsor, has agreed to support state-of-the-art immunological studies that will help understand the role of B cells in MS and the effect of the medication.

**Recombinant T Cell Ligand Therapy:** 

Two of the Centers, OHSU and Yale, have initiated a Phase I safety and dose finding study of the DR2-MOG 35-55 RTL, referred to as RTL1000. Patients with MS and who are positive for a specific marker (DR2+) will receive single i.v. infusions of RTL1000 of increasing doses (6-300 mg). The first patient has been enrolled. Outcomes will be safety, including MRI monitoring for disease activation and antibody formation to the RTL1000. This is the first step in developing RTL1000 as a novel immunotherapy for MS.

#### **Studies About to Start**

#### CTLA4-Ig:

Harvard is planning a multicenter phase II trial with CTL4-Ig based on the data reported last year for the phase I trial done at their center. CTLA-4Ig blocks T cell activation and suppresses inflammation. The data from the pilot study showed that CTLA-4Ig is safe in MS and there is evidence of biologic activity by changes in the immune markers in the blood.

# Sodium channel expression within human MS lesions:

Yale and Cleveland are examining the slow burn of axons in chronic lesions which have been implicated to play a major role in MS disability.

## SINGLE-SITE PILOT STUDIES

Some very novel agents are currently being developed by individual NDCWW centers. Single-site studies serve the valuable function of deriving preliminary data that, if encouraging, will come to fruition as larger collaborative trials.

#### Studies Completed In Past Year

The Oregon Health Center has completed the analysis of a single-site study of vaccination with a portion of the T cell receptor, Neurovax, that is well tolerated in patients with MS. This vaccine triggers a vigorous immune response to the vaccine and boosts regulatory cells in most patients. Further, two patients who reacted against brain myelin lost their reactivity on treatment. This study has provided data needed to successfully design the follow-up trial of this vaccine in MS.

The group at OHSU has completed a study of three different formulations of oral alpha lipoic acid in which 24 patients participated. One of the formulation gave the highest plasma levels of lipoic acid. This will lead to a study combining lipoic acid and interferon in patients with secondary progressive MS.

#### **Ongoing Studies**

#### <u>Neuroprotection with riluzole in early</u> <u>MS:</u>

UCSF has initiated one of the first studies with a neuroprotective drug, riluzole, in patients with early MS. Riluzole is an approved drug already shown to slow down Lou Gehrig's disease. Patients receive two year therapy with riluzole or placebo in addition to interferon beta-1a as a standard of care. Five patients have been enrolled in the study since January 2007. A total of 40 patients will participate to this study at UCSF. Sanofi-Aventis is providing free riluzole and placebo, and Biogen Idec is providing free interferon beta-1a. It is likely that OHSU will collaborate to this project if enrollment is slow at UCSF.

#### Salbutamol and Copaxone:

Following the finding that Salbutamol (used in asthma) decreases the release of IL-12, a pro-inflammatory product that is deleterious in MS, the group at Harvard has continued with their study of Copaxone plus Salbutamol to determine if the association enhances the antiinflammatory effect of Salbutamol. Being able to decrease the release of the pro-inflammatory product could prevent exacerbations of MS. Four patients are still in this study and will complete participation by December 2007.

#### <u>Omega-3 fatty acid in the treatment of</u> <u>depression and as an immunomodula-</u> <u>tor:</u>

OHSU is continuing with the study of omega-3 fatty acid in the treatment of depression in patients with MS and is also evaluating how this compound modulates the immune system in a way that could benefit to MS.

#### American ginseng for MS fatigue:

OHSU is continuing the study with American ginseng for treatment of MS fatigue. Twenty seven patients are currently participating to this trial.

#### High dose cyclophosphamide study:

Nine patients have been treated at Johns Hopkins with immunoablative doses of IV cyclophosphamide in patients with RRMS refractive to other therapies. The study will enroll a total of 10 patients.

#### **Studies About to Start**

#### Alpha Lipoic acid:

OHSU will test the pharmacokinetics of two other oral alpha lipoic acid formulations in the coming year so they can choose the best compound for the trial of oral lipoic acid as an adjuvant therapy to

(TRIALS continued on Page 11

#### ms health tips and resources

## MS Reference to Make Life Easier

Multiple Sclerosis: 300 Tips for Making Life Easier, 2nd Edition by Shelly Peterman Schwarz

There are exactly 300 tips in this book to make life easier with MS. Schwarz divides tips up into seven different categories, each of which gets its own chapter: General Tips; In Your Home; Look ing Good, Feeling Better; Managing Mealtime Madness; Taking Care of YOU; Managing Medical Issues; Weekend Getaways and Extended Travel.

Chapter 2, "In Your Home," begins with tip number 18: Rubber Bands. Yes, rubber bands. As Schwarz writes: "Rubber bands can add girth to handles on kitchen tools, hairbrushes and toothbrushes, and other household objects. Try adding rubber bands anywhere you need a little extra help gripping."

These are real-world practical strategies. Each chapter includes a resource list to easily locate anything that sounds particularly useful.Excerpt Review from Inside MS, August-Sept, 2006 by Dana Bard

## **Before You Fly**

Anyone with any disability has the right to travel in comfort, and you should know that there are resources out there to ensure your next flight is accommodating to your specific needs.

The US Department of Transportation (DOT) has a toll free hotline for Air Travelers with Disabilities (800-778-4838). The hotline has two main purposes: (1) education and (2) assistance in resolving disability related air-travel problems. Hotline operators are schooled in the Air Carrier Access Act and can provide travelers with general information about your rights. A suggested website that you can use as a resource: http://www.flying-with-disability.org/.

## Vitamin D and MS

Vitamin D supplements may positively influence the immune systems of patients with multiple sclerosis, Vitamin D status affects chemicals that modulate the immune system called cytokines, and these changes may benefit patients with multiple sclerosis.

A report from the long-running Nurses Health Study, from researchers at Harvard Medical School, now seems to back this theory. Women who had the highest vitamin D intakes, from supplements, were 40 per cent less likely to develop multiple sclerosis than those who used no supplements. The risk was found to be lowered among those getting most of their vitamin D from supplements and those who relied on supplements and diet for the vitamin. However, this study does not allow to conclude that vitamin D has a beneficial influence on ongoing multiple sclerosis. Furthermore it could not distinguish between a beneficial effect of vitamin D and multivitamin drugs including vitamin E and various B vitamins which may also exert a protective effect.

http://neurology.health-cares.net/multiple-sclerosis-vitamin.php

## **MSFriends**

MSFriends offers the first 24/7 peer support telephone helpline, staffed with volunteers who have MS. "Friends Helping Friends" is a lifeline that is immediate and offers MSFriends Guided Outreach to anyone, anywhere in the Continental USA at 1-866-MSFRIENDS (1-866-673-7436)

MSFriends offers online 1:1 peer support chat from 9:00 AM to 5:00 PM ET Monday through Friday.

MSFriends has a primary mission: to improve the quality of life for people with Multiple Sclerosis, for their families and friends. For more information visit: www.msfriends.org

## **Heat Busters**

Heat can cause symptoms to appear or make the ones you already have feel worse. It can affect walking, thinking, strength and energy levels.

As many as 60 to 80 percent of people with MS have had heat-related symptoms. One theory suggests that damaged nerves may conduct electrical impulses adequately under ideal temperatures but higher temperatures can interfere with the process.

Fortunately, the effects of heat are usually temporary. With hot weather, take time to assess your own sensitivity and find strategies that help you ease the effects of heat:

Stay in an air-conditioned environment during periods of extreme heat and humidity. If an air conditioner is needed to help minimize the symptoms of MS, the cost may be tax deductible if a physician has written a prescription for it. Use cooling products (vests, neck wraps, bandanas, etc.) during exercise or outdoor activity.

Exercise in a cool environment. Pick cooler times of the day or use air conditioning or a fan to help maintain body temperature.

Also, exercising in a cool pool. Wear lightweight, light-colored, loose, breathable cotton clothing and wide brimmed hats. Drink plenty of water. Icy drinks such as slurpees or popsicles can provide temporary relief. A cool bath or shower can help reduce core body temperature following activity or exposure to heat.

Don't be discouraged by the heat of the summer months. Find the strategies that work best for you, because you can beat the heat!

http://afterenlightenment.blogspot.com/2 007/05/managing-ms-beating-heat.html

#### **Beat Fatigue**

The best way to alleviate and manage fatigue is to maintain a regular exercise program.

If you have trouble with walking or with weight resistance, swimming is a great way to get exercise without putting a strain on your limbs.

Also, it is important to conserve energy when you know you will need a lot and in severe cases there are some medications on the market they may help with MS fatigue.

## Nutrition

It is suggested that multiple sclerosis patients make an effort to reduce their intake of saturated fat and eliminate trans fats from their diets. These fats increase inflammation in your body and can worsen MS symptoms. Try to eat fatty fish and other products such as flax oil, ground flaxseeds, and walnuts which contain a natural anti-inflammatory omega-3 fat. Other healthful monounsaturated fats include extra virgin olive oil, all-natural nut butters, dry roasted or raw nuts and seeds, olives, and avocados. Aim to eat nutrient rich carbohydrates as opposed to nutrient-poor carbohydrates. This means choosing unrefined carbohydrates such as whole grains, whole wheat flour, beans, potatoes, corn, fruits, and vegetables over processed foods containing refined flour and sugar.

Supplementation with a high quality multivitamin/ multi-mineral, calcium, vitamin D, and essential fats such as the GLA found in evening primrose oil and the EPA and DHA found in fish oil is also important. Finally, in order to minimize the negative functional effects of minor relapses it is vital to develop baseline musculoskeletal strength and balance through resistance training exercises such as yoga or light weight training. You should exercise in this manner for about 30 minutes three times per week.

Source: *The Gold Coast Cure*, Publisher Health Communications, Inc.

## Stress and MS

Disruption of the blood-brain barrier is thought to be involved in the development of multiple sclerosis (MS). The breakdown of this barrier precedes any clinical findings. Acute stress actually increases the permeability of the bloodbrain barrier through activation of brain mast cells.

There is some evidence that relapsingremitting MS attacks may be correlated with certain types of acute stressful episodes. Stress typically activates the brain through the release of a corticotropin-releasing hormone. However, acute stress also has inflammatory effects that appear to be mediated through the activation of mast cells.

Many MS patients have correlated their exacerbations with major stressful events such as divorce, car accidents or major illnesses or deaths in a family preceding months to their attack.

Source: MS Highlights, Issue 2, Vol.4-2001

When stress does manifest itself physically, it may cause muscles to tense up, leading to muscle spasms and poor balance. Mentally, it may cause depression or enhance symptoms causing a pseudoexacerbation. For these reasons, it is important to manage stress day-by-day and not let it build up.

There are many ways of coping with stress, such as excercise, meditation, soothing music, positive thinking exercises, counseling or therapy sessions.

Source: Sarah Beaubien http://ms.about.com/b/a/2005\_07\_25.htm



#### (RACE continued from Page 1)

Tom Arnold and Ross "The Intern" from *The Tonight Show* raised much needed funds as celebrity auctioneers at the night's exciting live auction. The highenergy auction featured a spectacular list of luxury items including a private dance lesson with Drew Lachey and Cheryl Burke from "Dancing with the Stars" and a fabulous trip to St. Regis Bora Bora which included airfare on American Airlines.

Among the guests were such superstars as Virginia Madsen, Apolo Anton Ohno, Joey Fatone, Nick and Drew Lachey, Ray Romano, Ian Ziering and Michelle Rodriguez.

Thank you to sponsors Makers Mark, Fiji Water, Wolf Blass Wine, Sapporo and Pierre Marcolini Chocolatier as well as Frederic Fekkai and MAC who created the amazing hair and makeup for the fashion show.

Thank you again to everyone involved in helping to make this evening such a grand success. Save the date May 2, 2008 for our 15th Anniversary event!

#### (TRIALS continued from Page 9)

oral lipoic acid as an adjuvant therapy to interferon beta for patients with secondary progressive MS.

#### <u>Ginkgo Biloba for cognitive impair-</u> ment in MS:

OHSU is about to start a study in 100 patients that will test Ginkgo compared to placebo for six months as a treatment of cognitive problems related to MS.

#### CTLA4-Ig:

Harvard is planning a phase II trial with CTL4-Ig based on the data reported last year for the phase I trial.

#### Anti-CD3 therapy:

Harvard is planning a phase I trial with oral anti-CD3 monoclonal antibody that suppresses the animal model for MS. This study will evaluate several doses of the medication and will determine if the therapy induces regulatory cells in the blood.

#### photo gallery, continued



Perry, Lynn Palmer, Tom Arnold and Jon Lovitz

Tara, Iris and Kaily Smith



Verdine White, Ralph Johnson, Nancy Davis, Donna Summer and Philip Bailey



dance to erase ms

Nancy Davis, Jerry Sanders and Laura Baumgarten





Autumn Bates with Friends



Lisa Rinna and Nancy Davis



Virginia Madsen, Tommy

Hilfiger and Dee Ocleppo



Apolo Anton Ohno and Julianne Hough



Suzie Sharrett and Paul Sharrett



Charles and Danica Perez, Iris Smith, David Foster and Yolanda Hadid



Lynn Palmer, Dee Ocleppo, Tommy Hilfiger, Nancy Davis and Ken Rickel



Barbara Davis, Marcy Taub, Nancy Davis, Kelsey Baker, Elaine Tack, Ann Cassidy



Friends with Cammie MacMillan, Jennifer Lustig and Michael Gardner



Chad Brownstein, Alexander and Julia Davis, Karen Sempertegui, Matt Winnick and Cass Brownstein



Larry and Kelly Thompson





Shaun Robinson and Keisha Whitaker



Laura and David McKenzie with Guests



Guest with Jason Davis, Que, and Bradley Spalter



Seth Green and Guest

Wanda Ruddy and Guest



Steven Cojocaru, Cindy and Steven Farber

#### **FALL 2007**

#### **PAGE 13**



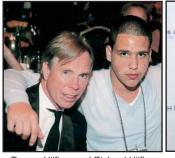
Jonathan Spanier, Gary Shapiro and Paul Rosenberg



Drew and Nick Lachey Ste



Steven Farber, Dr. James Sherman and Nancy Davis

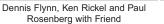


Tommy Hilfiger and Richard Hilfiger



Joey Lawrence







Michelle Rodriguez and Jack Rich



Jon Vinnick and Family



Sela Ward and Nancy Davis





Digby Diehl and Kay Diehl



Verdine White of Earth, Wind & Fire



Leonard III, Maria and Lenny Tambasco



Constance Zimmer



Shelly Uncer, Chitra Kirshnan and Cody Uncer



Mr. and Mrs. John Duran



Tracy Danza with Tom and Nancy Arnost



Dr. Brent Moelleken and Dayna Devon



Tia Carrere, Stacy Keibler, Giuliana DePandi, Daisy Fuentes, Lisa Rinna, Tara Reid, Keisha Whitaker



Melissa George



Guest with Dr. and Mrs. Andrew Frankel



Bill Rancic and Giulana dePandi



Dr. Dennis Bourdette, Dr. Stephen Hauser and Guests



John Elrod and Becky Hernreich



Chad and Cass Brownstein

#### brain exercise

# Image: Construction of the construc

#### ACROSS

- 1 A card that could save your life! (6 words)
- 3 Patchy areas of inflammation and
- demyelination. Not the type on your teeth!5 Possible factor in disease causation; chemical, emotional, physical.
- 8 Genentech drug that supresses B cells.
- 9 Legendary musical group that sings "Boogie
- Wonderland". 10 Comedian and sports genius, and an auctioneer
- at The Race to Erase MS. 12 Fabulous "Dancing With the Stars" dancer and
- former 90210 star who modeled in the
- Fourteenth Annual Race to Erase MS.
- 14 A cell that gives rise to other cells.
- 15 Unable to inhibit the muscle contractions.
- 17 Lowers cholesterol and helps with MS in early studies.

#### DOWN

- 2 Movement that greatly helps to relieve symptoms of MS.
- A Thread like transmitter of
- 4 Thread-like transmitter of impulses.5 Communication link between the brain and the
- nerves (2 words).
- 6 A temporary or permanent disappearance of symptoms.
- 7 Center Without
- 11 Similar to MS, almost exclusively affects the optic nerves and Spinal Cord.
- 19 An Olympic speed skater and winner of "Dancing With the Stars".

- 18 Band that performed at Dance to Erase MS and wants you to "Let Love In" as their popular single suggests. (3 words).
- 22 Fashionable 14 year sponsor of The Race to Erase MS.
- 25 Defense for the body (2 words).
- 26 Treatment for MS developed in Israel.
- 28 MS attack.
- 32 Repair or replacement of damaged Myelin.
- 33 Biogen MS Drug that starts with an A.34 Spinal Cord inflammation interfering with Nerve
- function below the level of the inflammation.
- 37 No sensations, for a short period of time.38 Singing brothers who modeled in the Dance to
- Erase MS fashion show. 39 Implicated in the destruction of myelin.
- 20 "She works hard for the money".
- 21 Medicine that gets rid of wrinkles, but might also help to relieve pain and spacticity.
- 23 Protective covering of our nerves (2 words).
- 24 Scars that form on myelin sheath.
- 27 One of the first nerves to be affected by MS.29 "Unforgettable" Grammy Award winner and 13th
- annual Race tp Erase MS performerr.
- 30 Required number of attacks for MS diagnosis.31 Theme song at Race events. (3 words).
- 35 Manufactured by Ares-Serono, that is similar to Avonex but administered differently.
  36 The Race to MS.
- 50 The Race to \_\_\_\_\_

# MULTIPLE SCLEROSIS:

Strikes twice as many women as men

Is extremely unpredictable

Diagnosed most often between ages 20 to 50

Can be permanently debilitating

Most common cause of neurological disability (excluding trauma) arising in early middle adulthood

# TRIBUTE CARD PROGRAM

Pay tribute to friends and family for special occasions and help us win the RACE to Erase MS!

We will send a card with your personal message to your friends and family on your behalf. It is a thoughtful gesture for a Birthday, Anniversary, Thank You, Speedy Recovery or any occasion.

See the self mailer included in this newsletter or gifts can be made by calling our office at (310) 440-4842.



\* For answers to crossword puzzle, please visit www.erasems.org

# **Risk Genes for MS Uncovered:** Center Without Walls Supported Study

Two new large-scale genomic studies have honed in on the main genetic pathway associated with multiple sclerosis (MS), while also uncovering new genetic variations in the disease and suggesting a possible link between MS and other autoimmune diseases. The first study, led by an international consortium of clinical scientists and genomics experts. incorporates the two largest collections of MS genetic information worldwide and is the first comprehensive study to investigate the overall genetic basis of MS. Its findings appear in the July 29, 2007 online edition of the "New England Journal of Medicine".

Another study is being published simultaneously on the web site of "Nature Genetics," and focuses on one variant in a gene called interleukin-7 receptor (IL-7R), which researchers had thought was connected to the disease and now know increases the risk of MS. "Scientists have known for 30 years that genetics play a critical role in MS, but the disease is influenced by so many different factors that it has consistently eluded us," said Stephen Hauser, MD, professor of neurology at the UCSF and an author on both papers. "It wasn't until we could map genomes and then combine the efforts of dozens of researchers, that we could put all the pieces together."

Together, he said, these two papers illustrate how scientific collaboration and the recent breakthroughs in genomic technology, which make it possible to both screen an individual's genetic architecture and understand the differences, can open up an age-old disease such as multiple sclerosis. It is significant that the two studies used very different approaches, but both highlighted the role of IL-7R, he said.

The consortium study, reported in NEJM, was co-led by researchers at UCSF and five other universities and medical centers in the United States and

England. The team analyzed genomic information from 12,360 people and confirmed that immune system genes are altered in people diagnosed with MS. It also pointed to potential mechanisms of the disease. Until now, the only genetic link identified with MS was in the major histocompatibility complex (MHC), a large cluster of genes responsible for many immune functions, including preventing the body's immune cells from attacking its own tissues. This analysis confirmed that link while also finding other variants in genetic regions that are more common in people with MS.

These advances are an outgrowth of a 15year effort at UCSF to create a national repository of more than 10,000 samples of DNA from people with MS and their families, the largest such collection nationwide. A similar database, in both quantity and quality, had been developed at the University of Cambridge, in England. Both collections were used for both of these studies.

But the real breakthroughs came through collaboration. Hauser said that individually, none of the six centers in the consortium could have completed a study of this scale and complexity, but funding they were able to form a truly effective international consortium that could deliver the most exhaustive search for MS risk factors ever published.

The international collaboration is currently planning even larger and more detailed explorations of the genetic landscape of MS and is now committed to making the entire data set available to MS researchers worldwide.

This work was supported by grants from The Nancy Davis Center Without Walls, the National Multiple Sclerosis Society, National Institutes of Health, the and the Penates Foundation.

For more information on UCSF, visit www.ucsf.edu.

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Every year 98,000 people in the United States die from preventable medical mistakes and 400,000 people are injured by these mistakes making this the sixth leading cause of death in our country.

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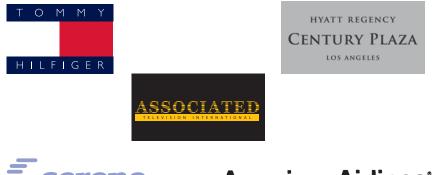
# 2008 MS Roundtable Saturday, May 3rd Hyatt Regency Century Plaza

Free to public. Open forum with our top MS research scientists speaking on the latest advancement in MS.

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The Nancy Davis Foundation for multiple sclerosis is dedicated to the treatment and ultimate cure of MS. Funding research is the core focus of the Foundation and significant strides have been made to find the cause and ultimate cure of this devastating disease.

All funds raised support "The **Davis Center Without** Nancy Walls", a selected network of the nation's top seven MS research centers. This nationwide collaboration of physicians, scientists and clinicians are on the cutting-edge of innovative research programs and therapeutic approaches to eradicate MS. It is the hope of the Foundation that in addition to combating MS through research in a clinical environment, an increased awareness will be created by educating the public about this mystifying disease.

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