

# Nancy Davis Foundation for Multiple Sclerosis

We are dedicated to the treatment and ultimate cure of MS. Funding research is the core focus of the Foundation and all funds raised support our Center Without Walls program, a selected network of the nation's top MS research centers. This nationwide collaboration of physicians and scientists are on the cutting-edge of innovative research programs, working as a team on therapeutic approaches to eradicate MS. In addition to combating MS through research in a clinical environment, we hope to increase awareness by educating the public about this mystifying disease.

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## Annual Gala: May 2, 2008

Co-Chairs Nancy Davis and Tommy Hilfiger celebrated the 15th Anniversary Race to Erase MS with a thrilling performance by Frankie Valli & The Four Seasons with special celebrity presenters Anne Heche, James Tupper, Tom Arnold, Lisa Rinna and Dr. Phil and Robin McGraw. The event was themed "We Heart to Erase MS". The event took place on Friday, May 2nd at the Hyatt Regency Century Plaza and raised over two million dollars for multiple sclerosis research thanks to a most generous group of supporters. Tommy Hilfiger Corporation, EMD Serono, Associated Television International, American Airlines, and the Hyatt Regency Century Plaza all contributed to the tremendous funds raised to support MS research.



Tommy Hilfiger Celebrity Fashion Show Finale

The highlight of the evening included an exclusive celebrity fashion show featuring one-of-a-kind inspired designs by Tommy Hilfiger, modeled by such celebrities as Aly & AJ, Lisa Rinna and Harry Hamlin, Garcelle Beauvais-Nilon, Keisha Whitaker, Shannon Elizabeth, Maria Menounos, Cheryl Ladd and Tara Reid. The amazing dancers from "Dancing with the Stars" kicked off the evening and a spectacular live performance by musical icon Frankie Valli & The Four Seasons who serenaded the crowd with their legendary tunes. The show's production was graciously donated by Associated Television International.



Tommy Hilfiger, Dee Ocleppo, Nancy Davis and Ken Rickel



Guest speaker, Teri Garr, with Presenter, Anne Heche

The ballroom was decked in modern white and vibrant orange by well known designer, Mindy Weiss, to compliment the iconic event theme. The extraordinary floral arrangements were generously donated by Marks Garden. Thank you to our sponsors Makers Mark, Fiji Water, Barefoot Wine and Bubbly, Asahi, and Frederic Fekkai and MAC, who created the amazing hair and makeup for the fashion show.

Tom Arnold and Lisa Rinna raised much needed funds as celebrity auctioneers at the night's exciting live auction. The high-energy auction featured a spectacular

**(RACE continued on Page 14)**

**"Yesterday is history, tomorrow a mystery, but today is a gift...that's why they call it the present." - Eleanor Roosevelt**

## 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 sixteen 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 sixteen 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 soon.*

*A cure is so much closer than I could have ever imagined. Hopelessness has been replaced by hopefulness.*

*The amazing doctors that are part of our Center Without Walls program have brought us to the brink of discovering the cause and a cure for this disease. Our newsletter is an educational forum to learn about the break-through discoveries these brilliant research scientists have accomplished this past year. I truly believe we must continue to push and fight to win this race against multiple sclerosis. With this belief we began our first MS month of May awareness campaign, Orange You Happy to Erase MS, utilizing the vibrant color of orange which we feel symbolizes hope. I am thrilled at the fabulous response we had this past May and look to all of our supporters who will help make May 2009 even more powerful in raising awareness.*

*The Center Without Walls commitment as a team to find a cure for MS is an inspiration to all of us, and I am so grateful for their diligent work. The support that the CWW receives from our amazing donors and supporters is more than I could have ever imagined. Thank you to everyone for your generosity and continued commitment to help us realize our dream and find a cure for MS"*

## Join our Network at **uPlej**

Go to <http://www.uplej.com/erasems> and start raising funds for Multiple Sclerosis research!

**uPlej (pronounced "you pledge") is a Professional Fund Raising Organization that combines social networking with charitable giving. For only \$4.79 per month everyone can afford to create your own uPlej user page and start giving back to charity! Then spread the word and tell others to do the same.**

**\$1 a month from each friend who joins your uPlej network will go to ERASE MS as well as \$1 from their friends and \$1 from their friends' friends.**

**Together we can raise a significant amount of money for the Nancy Davis Foundation for MS every month simply by connecting with other charitable individuals, businesses or charities. Join today!**

**Nancy Davis Foundation  
for Multiple Sclerosis**

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# MS Roundtable Forum

May 3, 2008



Lyndi Hirsch, Teri Garr, and Nancy Davis

Once a year the Nancy Davis Foundation for MS 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 as always is an important compliment to the previous evenings gala fundraising event.



Dr. Stephen Waxman and Claudia Curry Hill



Carmel and Ryan Giese with their son

This year, panel members included Dr. Dan Greenberg, Dr. Stephen Hauser, Dr. Richard Rudick, Dr. Emmanuelle Waubant, Dr. Stephen Waxman, Dr. Howard Weiner and Dr. Leslie Weiner, as well as distinguished guests Nancy Davis, Teri Garr, 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. "We don't compete, we communicate, share, and cross fertilize.... This is unique and the whole is much greater than the sum of it's parts" said Dr. Stephen Waxman of Yale University, underlining the importance of the Center Without Walls program.

We would like to thank our sponsors EMD Serono, Hyatt Regency Century Plaza, Le Pain Quotidien and Fiji Water for their invaluable donations towards this very important educational opportunity which is 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.



Panel from top left: Mark Barondess, Claudia Curry Hill, Nancy Davis, Dr. Emmanuelle Waubant, Dr. Ben Greenberg. From bottom left: Dr. Stephen Waxman, Dr. Richard Rudick, Teri Garr, Dr. Howard Weiner, Dr. Stephen Hauser, Dr. Leslie Weiner



Participants at the Hyatt Regency Century Plaza during MS Roundtable



Begyi Family with Nancy Davis



Dr. Emmanuelle Waubant speaks with participants of the MS Roundtable

# Shopping Event

July 16, 2008



Louis Van Amstel District Orange Pass Shops to Erase MS!

On July 16, 2008 the Nancy Davis Foundation for Multiple Sclerosis welcomed celebrity guests and foundation supporters to a cocktail party for the Melrose Place Shopping Benefit.

The cocktail party centered on the "Orange You Happy to Erase MS" shopping card – the "Orange Pass", which was available to purchase for \$75 with 100% of the proceeds going directly towards MS research and entitled the bearer to a range of discounts and benefits on fashion, beauty and dining in the Melrose Place District during the week of July 17, 2008. Participating stores included some of the most sought after boutiques in Los Angeles, adding excitement and glamour to our "Shop to Erase MS" event. Frederic Fekkai, Kate Somerville, Santa Maria Novella, Carolina Herrera, Diane Von Furstenberg, Diesel, Lambertson Truex, MAX&Co., Mulberry, Sergio Rossi, Mary Norton, Republic, Comme Ca, Dolce Enoteca e Ristorante, and Kumo donated their time and generosity to make this evening event a success.



Heidi Montag and Spencer Pratt



"Orange You Happy to Erase MS" items to buy!



Guests shopping at Lambertson Truex

photo gallery: We Heart to Erase MS



Jennifer Lucas and Byron Allen



Anne Heche, James Tupper, Nancy Davis, and Ken Rickel



Emmy Rossum, Tommy Hilfiger, and Dee Ocleppo



Cast from "Dancing with the Stars"



Nancy Davis with Frankie Valli



Julianne Hough



Katie Brass, Nancy Davis, and AJ Brass



Sheri Disney, Silvia Baker, Debbie Eaton, Markie Post, and Sherry Corday



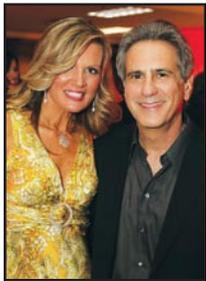
Ray and Anna Romano



David Horowitz (center) and Guests



Brooke, Jennifer, Debbie, and Jimmy Lustig



Lynn and Paul Palmer



Lisa Rinna



Cynthia Haro, Lisa Fitzmaurice, Diana Meyer, and Cathy Blazej



Amy Yasbeck and Guest



Aly and AJ Michalka



Kenny Rickel, Nancy Davis, Tommy Hilfiger, Dee Ocleppo, and Barbara Davis



Laura and David Mckenzie



Rick and Paris Hilton, Nancy Davis, Kathy Hilton



John Duran and Guests



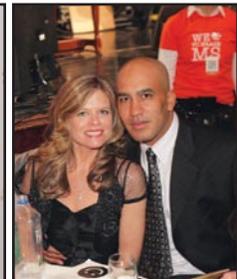
Mark Held, Nancy Davis, and Richard David



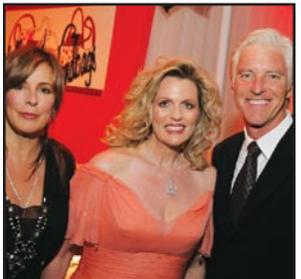
Arlene and Barry Hirschfeld, Debbie Lustig, and Pam McMahon



Louis Van Amstel and Kym Johnson



Stephanie and Bill Perkins



Victoria Jackson, Nancy Davis, and Bill Guthy



Maria Menounos and Nancy Davis



Carol Shelby, Darrell Pattillo, Debbie Pattillo, Kevin Shelby



Daisy Fuentes and Matt Goss



Debbie Lustig, Guest, Steve Farber, Barbara Davis, Jan Miller, and Arlene and Barry Hirschfeld



Samantha Harris



Jerry Sanders with Jennifer Lucas and Byron Allen



Alex Davis



Nicky Hilton, Nancy Davis, and Anne Heche



Aly and AJ Michalka



Katie Brass, Nancy Davis, Gellita Puck, and Jennifer Smith Hale



Ileana Douglas and Tom Arnold



Jason and Nancy Davis, and Tommy Hilfiger



Brenda Richie, Evelyn and Robert Rickel, and Kenny Rickel



Brandon Davis and Nancy Davis



Jerry and Tawny Sanders with Guests



Nancy Davis, Natasha Croxall, Margery St. John and Sahara Pynes



Dana Davis and Lynn Palmer



Iris, Michael, and Kailey Smith



Terry and Howie Mandel



Cammy and Deb MacMillan



Nancy Davis, Tracy Danza, Julie Araskog, Nancy Arnost, and Lynn Palmer



Lisa Rinna and Harry Hamlin



Claudia Curry Hill and Cheryl Fisher



Garcelle Beauvais-Nilon



Andrew Zucker, Lyndi Hirsch, and Harriet Sternberg

## highlights from the lab

# Center Without Walls Program Medical Research Update

The Nancy Davis Center Without Walls currently consists of seven of the top MS centers with complimentary expertise in multiple sclerosis research. The Nancy Davis Center Without Walls (NDCWW) is highly regarded nationwide as a leading consortium in the development of promising agents for multiple sclerosis (MS). The strategy of the NDCWW is first to evaluate novel treatment approaches in single-center or two-center studies which, if proven promising, are later developed collectively. In addition to trials of candidate agents for MS, the group is developing promising techniques to monitor more carefully the disease.

## Cleveland Clinic,

Director, Richard Rudick, M.D.



The Mellen Center has found that some immune communicating molecules called chemokines are key in the 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.

## 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 goals of the team at Johns Hopkins are to define the mechanisms by which axon injury occurs in MS and develop imaging biomarkers of axon and myelin injury. They are using classical inflammatory

animal models of MS as well as some novel non-inflammatory models in

which the myelin is genetically absent or chemically altered. These are providing information as to how axons that have lost their myelin die, e.g. because they are transected by immune cell derived enzymes, or because they have lost growth factor support from the myelin. The team at Johns Hopkins has found out that this occurs through different communication pathways and hopes to take advantage of the protective signals to devise axon protective therapies.

## 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.

## 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.

## Oregon Health Sciences University

Director, Dennis Bourdette, M.D.



In the past year, the team at OHSU continued its investigation of RTL1000, a novel therapy for MS developed at OHSU. The investigators have determined that

RTL1000 shifts the immune system from a pro-inflammatory state to a regulated state. This bioengineered protein is now in Phase I clinical trials. The team continued its groundbreaking research investigating how modulation of mitochondrial function can protect axons from injury in a mouse model of MS. Finally, the

OHSU team continues to be a national leader in the investigation of natural supplements, including lipoic acid, omega 3-fatty acids, American ginseng extract and ginkgo biloba, as therapies for MS.

## 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.

**THE RACE  
to  
ERASE  
MS**

## Pediatric Multiple Sclerosis

Emmanuelle Waubant, MD, PhD, UCSF

Although MS typically affects young adults with a peak of onset between ages 20 and 40 year, up to 10% of patients in fact develop their first MS symptoms before the age of 18. This is referred to as pediatric MS. Children as young as two years old have been diagnosed with MS.

Pediatric MS is under recognized by pediatricians and child and adult neurologists as it is relatively rare (between 10 and 20,000 cases in the USA) and very little has been published on disease presentation. Therefore, the diagnosis and initiation of preventative therapy are often delayed. In fact, families often see several care providers before the diagnosis is established, and are often stressed by how little information is available to them, as parents.

Establishing the diagnosis of MS in children is harder than in adults. Young chil-

dren typically do not appreciate that numbness from their waist down or decreased vision in one eye is not normal, unless symptoms are severe and interfere with their daily activities and become detectable by their parents. Thus mild symptoms may go unnoticed in young patients for a while. Also, as the awareness about pediatric MS is low in the medical community, patients may be diagnosed instead with hyperactive disorders or viral infections.

Although a couple of preliminary studies suggest that MS is less severe in children than in adults, patients reach similar levels of disability at a younger age, thereby affecting them during their most productive years of their lives when they are students or young parents. Furthermore, recent data collected in North America questions this notion of relative benignity of pediatric MS. The accumulation of  
**(PEDIATRIC continued on Page 15)**

## Complementary and Alternative Medicine for Multiple Sclerosis

Dennis Bourdette, MD, OHSU

Complementary and alternative medicine or CAM refers to a broad spectrum of treatments that most conventional physicians do not prescribe. CAM therapies include acupuncture, special diets, dietary supplements, such as herbs, megadose vitamins and fish oil, meditation, energy therapy and many more therapies. Up to three quarters of people with MS report taking one or more CAM therapies and often report deriving benefit from some CAM treatments. Despite this, conventional physicians, typically do not recommend any CAM therapies because up until recently there has been no scientific evidence to support using any CAM approaches.

Fortunately, research being conducted on CAM through the Nancy Davis Center Without Walls is beginning to determine what works and what does not. What

follows is a brief summary of some of this research that has been performed at Oregon Health & Science University.

We have demonstrated that people with MS can do yoga safely and it improves their fatigue and can be done safely. Yoga thus is beneficial for this MS symptom.

**Fish oil supplementation** The omega-3 fatty acids (called EPA and DHA) in fish oil have anti-inflammatory effects and may also improve depression. We are currently performing a research study to assess the effect of fish oil supplementation on proinflammatory proteins produced by white blood cells and to determine whether it improves depression when used along with anti-depressant medication. Taking a fish oil supplement

**(ALTERNATIVE continued on Page 15)**

# 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

#### Treatment that decreases B cells and antibodies against the nervous system

Several of the seven Centers have been involved in a new treatment strategy in primary progressive (PP) MS using rituximab, a monoclonal antibody against the B cell marker CD20 that depletes B cells for over 6 months after the first course of treatment. B cells are believed to contribute to MS brain inflammation and make antibodies against constituents of the brain. Although this study did not meet its primary endpoint in terms of statistical significance, there was a modest reduction in disease progression in PPMS patients who received rituximab compared to those who received placebo, particularly if they had experienced progression before enrolling in the trial. Rituximab recipients also had a lesser brain MRI progression over the 2-year period of the study. 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. Further studies will confirm whether some patients with progressive MS can benefit from this therapeutic strategy.

### Ongoing Studies

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

#### Lipitor (atorvastatin) for early MS

Eighty-three patients with their very first MS event have been enrolled nationwide in this study that evaluates the effect of Lipitor compared to placebo for one year

on MS activity measure by clinical examinations and MRI scans. Enrollment is complete, and the last patient in the study is expected to complete the last study visit at the end of 2008. 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 also sponsored by the Immune Tolerance Network, Biogen Idec and Pfizer.

#### Memantine - MS cognitive impairment

This year OHSU, in collaboration with USC, has conducted a double blind, 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. One hundred patients have completed the study. Data should be analyzed by the the end of 2008.

#### 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 positive for a specific marker (DR2+) will receive single intravenous infusions of RTL1000 of increasing doses (6-300 mg). The study should be completed next year. 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 CTLA4-Ig (Abatacept) based on the data reported last year for the phase I trial done at their center. CTLA4-Ig blocks T cell activation and suppresses inflammation. The data from the pilot study showed that CTLA4-Ig 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. The group was ready to follow-up with a clinical trial of an oral sodium channel blocker in patients with MS, but this study is on hold because of preliminary data in the animal model suggesting that a rebound may occur when discontinuing the drug. Additional data in animals are being acquired before starting the study in MS.

#### A study targeting macrophages

A multicenter phase I study involving UCSF, USC, Cleveland Clinic and OHSU will start at the end of 2008 to evaluate the safety and preliminary efficacy of a monoclonal antibody targeting macrophages in patients with relapsing-remitting and secondary progressive MS. This study is sponsored by Amgen.

## 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

#### Oral anti-CD3

Murine OKT3 monoclonal antibody is an approved therapy for the treatment of transplant rejection and humanized anti-CD3 monoclonal antibody has shown positive clinical effects in new onset diabetes in humans. Based on animal studies, the group at Harvard has tested the effect of oral administration of murine OKT3 in 18 healthy human subjects for 5 days. Immune effects were observed in all subjects with the most consistent responses observed at the 1.0 mg dose. No side effects were observed. These findings demonstrate that oral anti-CD3 monoclonal antibody is biologically active in humans and is applicable for the treatment of human autoimmune diseases such as MS. A follow-up study is in the planning for next year to evaluate various dosages.

#### CTLA4-Ig

The modulation of co-stimulatory pathways represents an original therapeutic approach to regulate T-cell mediated autoimmune diseases by preventing or reducing auto-antigen driven T cell activation in humans. The group at Harvard has used CTLA4-Ig intravenous infusions to block the CD28/B7 T cell co-stimulatory pathway in a phase I, dose escalation study in MS. Sixteen patients with relapsing-remitting MS received a single CTLA4-Ig infusion and 4 additional subjects received 4 doses of CTLA4-Ig. Inhibiting co-stimulatory molecule interactions by using CTLA4-Ig appears safe in MS and the immunologic effects suggest that it may be a promising approach to regulate the inflammatory processes associated with MS. The center at Harvard is following up with the design of a larger scale study to confirm their findings.

#### Alpha lipoic acid

The group at OHSU has completed a study of three different formulations of oral alpha lipoic acid in which 40

patients participated. One of the formulations 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.

#### 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. This aggressive treatment approach seems promising for very active MS. A confirmatory study is in planning.

#### Daclizumab

This monoclonal antibody blocks T cell activation and induces a unique type of regulatory cell. The group at Harvard has completed an open-label study of 59 patients which shows that a majority of patients benefited

### Ongoing Studies

#### Neuroprotection/ riluzole in early MS

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 years of therapy with riluzole or placebo in addition to interferon beta-1a as a standard of care. Twenty-one patients have been enrolled in the study since January, 2007. A total of 40 patients will participate in 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 in this project if enrollment is slow at UCSF.

#### Omega-3 fatty acid in treatment of depression & as an immunomodulator

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. Forty-two patients have been enrolled.

#### American ginseng for MS fatigue

OHSU is currently analyzing the results of the study performed with American

ginseng for treatment of MS fatigue. Results are expected in the fall 2008. Forty-two patients participated to this trial.

#### Functional imaging of episodic memory dysfunction in MS

The group at the Cleveland Clinic is developing a novel strategy of imaging to improve our understanding of memory dysfunction in MS.

#### Optical Coherence Tomography

Several of the groups, including Cleveland Clinic, Johns Hopkins, UCSF and USC are investigating whether a new painless technique called optical coherence tomography that measures the nerve fiber layer in the back of the eyes is correlated to several MRI measures and whether it reflects well nerve tissue damage.

### Studies About to Start

#### Alpha Lipoic acid

OHSU will test oral alpha lipoic acid in the coming year as an adjuvant therapy to interferon beta for patients with secondary progressive MS. The study protocol is being finalized.

#### Ginkgo Biloba for cognitive impairment in MS

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

#### 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.

#### Vitamin D replacement

The group at Johns Hopkins is planning to start the evaluation of immunological benefits of high dose vitamin D replacement in MS.

## On the Cusp of a New world: MS Gene Pioneer Dr. Stephen Hauser Shares his Vision

Excerpts By Sara Bernstein

"This is a time of great momentum," said Stephen L. Hauser, MD. "We are at the cusp of understanding the genetic basis of MS with a resolution that we could never have imagined just two or three years ago." Dr. Hauser would know; he has received the National MS Society/American Academy of Neurology's 2008 John Dystel Prize for MS Research in recognition of two decades of pioneering studies on genetic susceptibility to MS.

Dr. Hauser's excitement about MS genetics is due to the work of the International Multiple Sclerosis Genetics Consortium (IMSGC), a group of international MS genetic experts created with funding from the Society.... Not only will we have a 'dictionary' of the genes that are important in MS, but much more significant, this information is likely to transform our understanding of just how MS begins." Although Dr. Hauser surmises that there are probably 50 or so susceptibility genes for MS, he believes that identifying these genes will not complicate the MS picture, but will lead us to a much simpler view of disease pathways, better treatments, and prevention.

Dr. Hauser hopes to follow up this genetics effort with a study of people who can be identified as being at increased genetic risk for MS. Investigators would seek to identify a series of changes in the immune system that occur before the damage to nerve-fiber insulating myelin-the hallmark of MS-begins. "Armed with new genetic knowledge and insight from immunology, we should be able to identify people at risk for MS and understand the very first steps," said Dr. Hauser. "Wouldn't it be wonderful to prevent MS before it begins?"

Long interested in the immune activity that underlies MS, Dr. Hauser published seminal findings associating antibodies (proteins produced by B cells) with damage to the myelin. (Nature Medicine 1999 Feb;5[2]; 170-5) These lab findings resulted in a clinical trial of rituximab (Rituxan, from Genentech and Biogen Idec), a drug that depletes B cells.

"The development of rituximab has been thrilling," said Dr. Hauser. "We found that treatment was effective against relapsing-remitting MS beyond what we had imagined." Dr. Hauser and colleagues reported that one course of this intravenous drug reduced disease activity -for 48 weeks in people with relapsing-remitting MS, a course of MS characterized by clearly defined flare-ups followed by partial or complete recovery periods. (The New England Journal of Medicine 2008 Feb 14;358[7]; 676-88).

Dr. Hauser looks forward to a bright future in MS research, where novel collaborations and therapeutic strategies are bringing us closer to a world free of the disease. "These exciting new developments could change the face of what is possible for people with MS," he concluded.

Resource: *Momentum*, Fall 2008

The Nancy Davis Foundation for MS is proud to support the research of Dr. Stephen Hauser at UCSF and we congratulate him on the prestigious award of the National MS Society/American Academy of Neurology's 2008 John Dystel Prize for MS Research.

Thank you Dr. Stephen Hauser for your passion to find a cure for multiple sclerosis!

## Center Without Walls Collaborating Physicians

**Dr. Jack Antel**,  
Montreal Neurological Hospital

**Dr. Rob Bakshi**  
Brigham & Women's Hospital

**Dr. Guy Buckle**, Harvard  
Brigham & Women's Hospital

**Dr. Michael Carrithers**,  
Yale University

**Dr. Tanuja Chitnis**, Harvard  
Brigham & Women's Hospital

**Dr. Jeffrey Cohen**,  
Cleveland Clinic

**Dr. Kathy Conant**,  
Johns Hopkins

**Dr. George Eisenbarth**,  
University of Colorado,  
Health Sciences Center

**Dr. Elizabeth Fisher**,  
Cleveland Clinic

**Dr. Bob Fox**,  
Cleveland Clinic

**Dr. Suzanne Gauthier**, Harvard  
Brigham & Women's Hospital

**Dr. Wendy Gilmore**,  
University of Southern California

**Dr. Ari Green**,  
University of California, San Francisco

**Dr. Charles Guttman**, Harvard  
Brigham & Women's Hospital

**Dr. Halina Hoffner**,  
Oregon Health Sciences

**Dr. Norman Kachuck**,  
University of Southern California

**Dr. Samia Khoury**, Harvard  
Brigham & Women's Hospital

**Dr. Jeff Kocsis**,  
Yale University

**Dr. Brian Kotzin**,  
Amgen

**Dr. Brett Lund**,  
University of Southern California

**Dr. Gerald Nepom**,  
Virginia Mason, Seattle

**Dr. Jorge Oksenberg**,  
University of California, San Francisco

**Dr. Daniel Pelletier**,  
University of California, San Francisco

**Dr. Jana Preiningerova**,  
Yale University

**Dr. Richard Ransohoff**,  
Cleveland Clinic

**Dr. Daniel Reich**,  
Johns Hopkins

**Dr. William Rooney**,  
Oregon Health Sciences

**Dr. Bruce Trapp**,  
Cleveland Clinic

**Dr. Arthur Vandenbark**,  
Oregon Health Sciences

**Dr. Arun Venkatesan**,  
Johns Hopkins

**Dr. Ruth Whitham**,  
Oregon Health Sciences

**Dr. Scott Zamvil**,  
University of California, San Francisco

## ms health tips and resources

**300 Tips for Making Life Easier, 2nd Edition**

Shelley Peterman Schwarz

This completely revised second edition of *Multiple Sclerosis: 300 Tips for Making Life Easier* contains tips, techniques, and shortcuts to help MS patients organize and simplify their lives. From basic principles to unique solutions for saving time and energy to specific ideas, this book is packed with helpful information for those coping with the special challenges of a chronic illness. Updated chapters cover Home Safety and Accessibility, Computers and Technology, Looking Good, Feeling Better - Grooming and Dressing, Managing Mealtime, and much more. NEW sections include: Managing medical issues Travel tips for weekend get-aways or extended travel Unique product suggestions for practical helpful items that make everyday tasks easier Resource section to easily locate products and services

*Multiple Sclerosis: 300 Tips for Making Life Easier, 2nd Edition* is a valuable resource for individuals living with MS, family members, caregivers, and medical professionals.

[http://www.demosmedpub.com/prod.aspx?prod\\_id=9781932603217](http://www.demosmedpub.com/prod.aspx?prod_id=9781932603217)

**Fish Oil and MS**

According to researchers from Oregon Health & Science University, fish oil has been shown to ease the symptoms of MS. Patients with multiple sclerosis who were given fish oil found that their symptoms improved significantly and the levels of inflammatory proteins in their blood was down nearly 60 percent. "The findings confirm previous research findings that suggest the intake of fish oil containing omega -3 fatty acids could provide a measure of relief for those with MS," the investigators conclude.

Resource: NE September 17, 2007

**Fear, Anger, Depression**

Dealing with fear, anger, and depression can be the result of the effect of MS on the brain. But these are also natural emotions that come from dealing with the unfairness of losing what we may have thought of before as a "normal life." While such feelings may be inevitable, their persistence can be harmful. Be as honest with yourself as you can. This means not denying reality or creating false expectations. Develop a positive attitude by thinking about things that can be done instead of things that cannot be undone. Do volunteer work, help a friend or relative in time of need. All of these things can have a therapeutic effect. Hope and acceptance come when you realize that MS is now another part of you and doesn't define you – and that life is about today and less about yesterday or tomorrow.

<http://www.mswatch.ca/community/section.aspx?SectionId=689b4448-a836-4a8d-97db-0bd0d6d2b980>

**MS: Eating Right**

Healthy eating is important for everyone, but it is particularly important if you have a chronic illness, such as multiple sclerosis. What Are Some Basic Nutrition Guidelines for People With MS? 1) Eat a variety of foods from each food group; maintain your weight through a proper balance of exercise and food. 2) Choose foods low in saturated fat and cholesterol, unless otherwise directed by your healthcare provider. 3) Try to limit how much sugar you eat and moderate your use of salt. 4) If you choose to drink alcoholic beverages, do not consume more than one or two beverages per day. 5) Drink eight 8-ounce glasses of water per day and limit caffeine consumption.

Reviewed by the doctors at the Mellen Center for Multiple Sclerosis Research at The Cleveland Clinic.

Resource: [www.webmd.com/multiple-sclerosis/guide/multiple-sclerosis-eating-right](http://www.webmd.com/multiple-sclerosis/guide/multiple-sclerosis-eating-right)

**Two Steps Forward**

Forbes, September 1, 2008

Robin Giese, 59, Kicks off each day by getting out of her wheelchair for a half-hour ride on a stationary bike followed by 30 minutes of stretching exercises....Giese hasn't always been so active. She has multiple sclerosis...Over three decades multiple sclerosis has slowly robbed Giese of her mobility and weakened her muscles, and without treatment she would be all but immobilized in her wheelchair. But an experimental drug has changed the course of her disease and her husband's career path.

The compound, called dirucotide, is a chain of 17 amino acids that mimics a portion of the protein in myelin. It works by acting as a decoy to divert the attacking immune cells. It has had such a profound impact on Robin's condition that her husband has started a company, BioMS Medical, to bring it to market.

Today dirucotide is one of two novel MS drugs in late-stage clinical trials. Most existing MS therapies work by suppressing the immune system, and they're generally effective only when the disease is at an early stage.

Dirucotide began with research conducted at the University of Alberta by doctors Kenneth Warren and Ingrid Catz. In 1989 Warren developed a synthetic peptide that mimics myelin protein.

The results so far have been very promising. Patients with either of two genes associated with autoimmune disorders, HLA-DR2 and HLA-DR4, have gone five years without any progression of the disease. Those genes are found in 65% to 75% of all MS patients, and because of that analysts estimate that the potential market for drugs like dirucotide, effective for patients at later stages of the disease, could reach \$10 billion a year. The current market for all existing MS drugs is \$6 billion.

Forbes, September 1, 2008.

photo gallery, continued

We Heart to Erase MS



Michael Fredo with Kim and Andy Hilfiger



Michael Smith, Beny Alagem, and Kenny Rickel



Aly and AJ Michalka with Guests



Marcy Taub and Lynn Palmer



Eric Benet with Guest and Michael and Iris Smith



Katie Brass and Nancy Davis, and Friends



Shannon Elizabeth



Emma Sharratt and Guests



Dean Singleton with Guests



Elaine Tack, Shannon Cassidy and Nancy Davis



Jan Miller, Gary Gilbar, and Pepita Serrano



Anne Heche and Nancy Davis



Alagem Family



Sherry Corday and Robin Correll



David and Beth Horowitz



Jillian Barberie and Grant Reynolds



John and Jordan Davis, and Julie Araskog



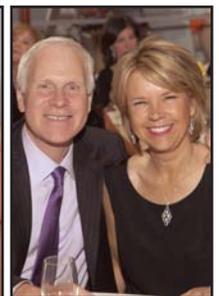
Robin Broidy and Nancy Davis



Deb MacMillian Family and Guests



Emmy Rossum and Nancy Davis



Steven and Jennifer Pal



Jack Rich and Ali Landry



Dr. Stephen Hauser, Dr. Elizabeth Robins, Elaine Hauser, Nancy Davis



Tara Reid



Mary Virginia Knight and Henry Fong



Cheryl Ladd



Jeremy & Caroline Finkelstein, Stephanie & Ernie Cockrell, and JoAnna Barrett with Guest



Kelly Hu and Maria Menounos



Julianne Hough, Nancy Davis, and Derek Hough



Angelica Castro, Cristian de la Fuente, Nancy Davis, and Chuck Binder



Marky Ramone



Guests with Karen and Dr. Gary Richman



Nancy Davis and Penny Marshall



Yaara Elisha and Will MacMillan, Jr.



Judith and Dr. Leslie Weiner, Guest with Luci Lawrence



Josie Bissett



Adele and Beny Alagem



Keisha Whitaker



Mary Conner (center) with Guests



Kristi Yamaguchi and Mark Ballas



Dana Davis, Tony Williams, and Barbara Robinson



Rose, Mark, and Andrew Barondess with Lynn Palmer



Nick Chavez and Guest



Wendi and Dan Goldman with Nancy Davis and Andy Gelb



Leeza Gibbons



Sue and Paul Sharratt with Guests



Ceron with Alexandra and Brady Knight



Uyen and Brad O'Leary



Marlee Matlin (center) and Guests



Claude and Alfred Mann



Roxane Begyi and Susan Neisloss



Avi Cohen, Tova Celine and Nancy Davis

## from our supporters



Ana Randall

**School Essay Contest Winner!**

Ana Randall entered an essay contest in her 7th grade class at Marshall Middle School in which a \$50 check would be sent to the charity or cause that was written about in their essay. Ana won! The check was gratefully received by the Nancy Davis Foundation for MS. Thank you Ana for writing such a wonderful essay in support of your father and the foundation. Enjoy Ana's winning essay:

"Imagine finding out that someone you love or know can become blind or paralyzed any day of their life. I know that feeling because my dad has multiple sclerosis. Multiple sclerosis, or MS, is the erosion of your meniscus, or the spinal coating that protects your nerves. The erosion is caused by your body thinking that your meniscus is dangerous, therefore it attacks it, causing the lesions. If treatment is not given though MS can cause numbness, heat intolerance, blindness, and in the long run death.

That is why I would like to give our money to the Nancy Davis Foundation for MS. The Nancy Davis Foundation helps find a cure, while it empowers families to have hope.

Imagine having to pay for the weekly shot, while living in a low income family, it would really take its toll. That is why I would like to give our money to the Nancy Davis Foundation, so that we could help everyone with MS.

So that is why I would like to have our money be given to the Nancy Davis Foundation. So no other child or parent will have to know the pain of losing a loved one. Thank You."

**(PEDIATRIC continued from Page 7)**

disability in pediatric cases in North America seems more rapid than previously described, challenging the benign nature of the disease. It is unclear whether this is in part explained by a different ethnic background in children: half of the pediatric MS patients in North America are not white, compared with 20% of adult MS patients.

Finally, it is also possible that there is an increased risk to develop MS in children who are coming from ethnic groups in which typically the disease is rare. It remains to be determined whether this is related to environmental factors or genetic background or both. For a long time physicians did not feel comfortable treating children with MS with drugs approved for adult MS as no data were available regarding safety of these drugs. There is now reasonable information gathered over the past 10 years on the tolerability of interferon and Copaxone. This has resulted in the larger use of these agents in children who develop an active form of MS. Whether these agents are as beneficial in children as in adults remains to be found.

**(RACE continued from Page 1)**

list of luxury items including a Harley Davidson designed by Tommy Hilfinger and an Ultimate Parisian fashion experience which included first class airfare on American Airlines.

Among the guests were such superstars as Howie Mandel, Ray Romano, Anne Heche, Emmy Rossum, Paris and Nicky Hilton, Shannon Elizabeth, Maria Menounos and James Tupper.

Thank you again to everyone involved in helping to make this evening such a grand success. Please make sure to save the date of May 8, 2009 for our 16th Annual Race to Erase MS at the Hyatt Regency Century Plaza!

**The MonSter**

A poem by Michele Chambers

You sometimes see the way I walk  
 You sometimes tell the way I talk  
 But you look fine I always hear  
 Then I say those words you fear  
 It conjures visions many dread  
 The MonSter's reared its ugly head  
 Some diagnosed in time to fight  
 Yet those like me too late just fright  
 You sit with hope, fear and terror  
 That maybe it was done in error  
 Those two slight letters evoke distress  
 That inescapable phrase, "you have MS"  
 I cannot work, I cannot run  
 You'll hardly find me in the sun  
 Those years the Doctor didn't see  
 The MonSter had control of me  
 The tingling comes in dead of night  
 You try to rest with all your might  
 The pain you feel you can't express  
 Being tortured though you can't confess  
 With its own rules this MonSter goes  
 And mercy's not a word it knows  
 You want to scream and beg why me  
 But MonSter does not care you see  
 So I smile, and say I'm fine  
 This misery must be just mine  
 Those strangers, their disgusted leers  
 Will almost always bring the tears  
 I've learned to rant and cry inside  
 The healthy rules I must abide  
 An injection I now take each day  
 The pain on pain a price I pay  
 To keep the MonSter slight at bay  
 No more attacks each night I pray  
 Though each new day as I awake  
 Each leg I shake, a chance I take  
 One eye I have, I beg I'll see  
 The MonSter did not visit me  
 My battles lost, but not the war  
 I'm hoping many years to for  
 Though I may slur and sometimes fall  
 I won't give in to MonSters call

Thank you to Michelle for sharing her poem with us and we appreciate her email and support of the Nancy Davis Foundation for Multiple Sclerosis!

# "ORANGE YOU HAPPY TO ERASE MS" Month of May MS Awareness Campaign

**Together we can heighten awareness for multiple sclerosis and bring hope to those affected by this disease.**

**With the support of fabulous retailers we will have a spectacular collection of items in the signature MS orange - the vibrant color of hope - for purchase in support of educating the community and funding MS research.**

**Visit us at [www.erasems.org](http://www.erasems.org) during the month of May and propel us one step closer to finding a cure for multiple sclerosis. For more information on how to help contact us at 310-440-4842 or [info@erasems.org](mailto:info@erasems.org).**

**(ALTERNATIVE cont. from Page 7)**

that provides 1-2 gm/day of EPA and 0.5-1 gm/day of DHA is safe and may be beneficial.

**Ginkgo biloba for memory problems** We have completed a small double blind placebo controlled trial of ginkgo biloba (120 mg twice a day) for memory problems in MS. This study suggested that ginkgo biloba was safe and beneficial. We have started a much larger placebo controlled trial involving 100 volunteers with MS to prove that it is helpful.

**Lipoic acid** Lipoic acid is an orally active anti-oxidant that is effective in treating mice with an experimental, MS-like disease. We have shown that taking lipoic acid (1200 mg once a day) produces therapeutic blood levels of the anti-oxidant and lowers proteins associated with MS disease activity.

**American ginseng extract** We recently completed a placebo controlled trial of American ginseng extract to determine whether it is effective in improving fatigue in MS. The results of this trial will be available this coming fall.

**Research on CAM** is important because it will demonstrate what works and what does not. Support provided to scientists through the Nancy Davis Center Without Walls is helping to advance this important research.

## 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.**



Actual Card

**It is a thoughtful gesture for a Birthday, Anniversary, Thank You, Speedy Recovery or any occasion.**

**See the self mailer included in this newsletter, go online [www.earsems.org](http://www.earsems.org), or gifts can be made by calling our office at (310) 440-4842.**

## Protect Yourself and Your Family

*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.*

My Very Necessary Medical I.D. Card™ fits easily in your wallet and contains your most essential medical information in case of an emergency when you can't speak for yourself. Our service allows you to store and retrieve your medical and legal records and will assist in reducing healthcare inefficiencies, limit the possibility of medical errors, and ensure one's legal wishes. We have developed a safe and secure method to organize, store, and immediately access one's important medical information and legal wishes from anywhere in the world by using the internet or calling one of our customer service associates 24/7. My Very Necessary Medical I.D. Card™ has partnered with AccessMyRecords.comSM to offer you this valuable service.



[www.vnmedical-idcard.com](http://www.vnmedical-idcard.com)  
**800-796-6431**

## Lamborghini

### 2009 Exclusive Auto Sponsor



We are pleased to announce Automobili Lamborghini S.p.A. as our exclusive automobile sponsor of the 2009 Race to Erase MS event. Lamborghini will be donating one of its newest super sports

cars as well as a personal tour of its birthplace; the historic Lamborghini factory in Sant'Agata Bolognese, Italy to our Live Auction. Working together, Lamborghini and the Nancy Davis Foundation for MS will partner to raise record funds to fight this debilitating illness.

Lamborghini's DNA is characterized by its origin. No other region in the world is as intensely formed by the passion for the fine sound of high-performance engines as the region of Emilia Romagna in northern of Italy.

The design of a Lamborghini is always unique. Even when presented for the first time, every new Lamborghini is intrinsically destined to become a future legend and a sought-after classic.

The Lamborghini will be featured in the Live Auction on May 8, 2009 at the Hyatt Regency Century Plaza during the Race to Erase MS event. For information on tickets and sponsorships, please call the Nancy Davis Foundation at (310) 440-4842 or email [info@erasems.org](mailto:info@erasems.org).

## 16th Race to Erase MS Gala

### Friday, May 8, 2009

## Hyatt Regency Century Plaza

For more information please call 310-440-4842 or visit [www.erasems.org](http://www.erasems.org)

## 2009 MS Roundtable

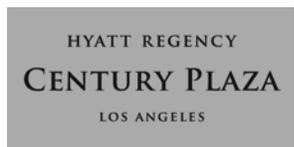
### Saturday, May 9th

## Hyatt Regency Century Plaza

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

## Major Sponsors

Thank you for your generous support!



### Nancy Davis Foundation for Multiple Sclerosis

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