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.

Fall 2011

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Nancy Davis Foundation for Multiple Sclerosis

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18th Gala Rock and Royalty Erase MS



RACE On Friday, April 29th, Nancy Davis welcomed guests to the Hyatt Regency Century Plaza for the 18th Annual Race to Erase MS. The event raised more than \$2 million to benefit our Center Without Walls program and MS research. The 18th Annual Race to

Erase MS themed Rock and Royalty opened with an exciting celebrity fashion show featuring a sneak preview of Andrew Charles, the new hip rock 'n' roll fashion line by Andy Hilfiger. Following the fashion show, Andy Hilfiger surprised the crowd by performing



Joan Jett and the Blackhearts rock the house!

"Jumpin Jack Flash" with his band. Cindy Crawford and Bill Maher introduced our talent. The evening also included a live auction hosted by Shaun Robinson and Mark Curry. Paris Hilton helped start the auction off with a shopping spree and lunch with her sister Nicky Hilton on Robertson Blvd. Items such as a private yacht trip and an African Safari were big sellers for the evening. At this year's gala we honored MS survivor Katie Mattingly Brass and William O. "Bill" Perkins for their outstanding contributions to funding vitally important multiple sclerosis research.



Clay Walker and Nancy Davis

In a nod to the event's royal theme since the event took place on the same day as the Royal Wedding, A.B.S. by Allen Schwartz unveiled a one-of-a-kind exclusively designed wedding gown inspired by the Royal Wedding Gown worn by Kate Middleton only twelve hours before as well as an almost identical version of Pippa's maid of honor dress. Led by musical director Rickey Minor, the Race to Erase MS once again hosted a variety of musical performances throughout the evening. Joan Jett and the Blackhearts entertained the crowd with everyone on their feet dancing with many outstanding ovations to an exciting set including "I Love Rock 'N Roll." Country music star and MS survivor Clay Walker closed out the evening with a performance of songs including "Honkey Tonk" while guests danced the night away. In Race to Erase MS tradition, the night ended with a performance of "Lean On Me" featuring Clay Walker, David Osmond, Debbie Gibson

and BG5. Guests couldn't leave without picking up the coveted Race to Erase MS gift bag donated by Tiger J filled with over 50 unbelievable items, enjoying Don Francisco's coffee and delicious cupcakes courtesy of Gilt City Los Angeles while they waited.

We would like to thank our amazing presenting sponsors Tommy Hilfiger, American Airlines, EMD Serono, Pfizer, Hyatt Regency Century Plaza and Associated Television International for their generous support year after year. Our event sponsors were truly instrumental in making the Race to Erase MS an electrifying evening. The extraordinary orange floral arrangements were generously donated by Marks Garden. Mindy Weiss, well known event designer, decorated our auction in the most royal fashion to reflect the theme of the event. Thank you to Absolut, Lookout Ridge Winery, FIJI Water and POM for their wonderful array of beverages. Thank you to Cristophe Salon and MAC, who created the amazing hair and makeup for our celebrity presenters and fashion show participants. Thank you to everyone for your infinite generosity and help in finding a cure for Multiple Sclerosis. Save the date May 18, 2012 for our 19th Annual Race to Erase MS at the Hyatt Regency Century Plaza!

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Message from Nancy Davis

President and Founder



"We are so proud and enormously grateful for the amazing and wonderful support year after year from our very generous and dedicated donors. You will never know just how important each and every one of you are in helping find a cure for MS. I know once a year we ask for your

help with this very important, life changing cause and you always welcome us with open arms, a smile on your face and give so generously from your hearts.

Funding research grants to Young Investigators (YI) is a priority for all of us as we strive to support the brightest and most innovative research to lead us to a cure for MS. Ground-breaking basic science is the heart of the YI program and without support from our Center Without Walls, these young scientists would be lost to private practice. It is vitally important to support YI research endeavors to ensure we will win our Race to Erase MS. We are proud to fund six YI awards for the 2011-2012 year and our grantees are profiled in this issue for your interest.

I am so grateful for the continued support of "Orange You Happy to Erase MS" month of May Campaign Partners, celebrity supporters and media who helped us raise important funds for MS research. And we thank those who support our efforts year round. Make sure to visit our website at www.erasems.org and click on SHOP!

We are also honoring Deb and Bill MacMillan, true and sincere philanthropists in every sense of the word, and Teri Garr, an inspiring role model, legendary actress and member of our Board. We are thrilled they have agreed to be honored for their generous and charitable work at our 2012 Race to Erase MS event. Please save the date for our 19th Annual event on May 18, 2012!



Center Without Walls Scientific Advisory Board

Welcome to our new team!

We are thrilled and honored to welcome three of the most prestigious doctors in the country to our Center Without Walls Scientific Advisory Board (SAB). Dr. Henry McFarland, Dr. Luanne Metz and Dr. Daniel Reich are truly the most stellar team of brilliant minds who will continue to lead our foundation in supporting ground breaking research initiatives. I met with our new SAB this past May in Washington DC during a neurological conference and I am truly in awe and inspired by their collaborative perspective and passion to fund only cutting edge research proposals.



Dr. McFarland, among his other prestigious recognitions, served as Chair of the Medical Executive Committee as well as the Advisory Board for Clinical Research that is advisory to the Director, National Institutes of Health in shaping the future direction of clinical research at National Institutes of Health.



Dr Luanne Metz is a Professor in the Department of Clinical Neurosciences at the University of Calgary. She is most known for her development of the Calgary MS Clinic which she serves as Director as well as the Co-Leader of MS Program of the Hotchkiss Brain Program.



Dr. Daniel Reich is an Investigator at the Translational Neuroradiology Unit, at Johns Hopkins which is developing new MRI methods to investigate the origin of disability in MS and related disorders and applying those methods to patient care and to clinical trials of new drugs.

We congratulate them on helping to break down barriers and create excellent communication with no duplication of basic science research, bringing us one step closer to finding a cure. We are so appreciative of our stellar new team who will continue to lead our foundation in funding only the highest quality of research to expedite our mission to Erase MS!

SAVE THE DATE!

19th Annual Race to Erase MS Gala Friday, May 18, 2012

Join us for our star-studded evening to raise funds for MS research! For Tickets and Sponsorship Opportunities please call 310-440-4842 or visit www.erasems.org.

Announcing Honorees for 2012 Race to Erase MS! **Deb and Bill MacMillan and Teri Garr**

We are thrilled to announce legendary philanthropists Deb and Bill MacMillan and actress Teri Garr as our honorees at our 19th Annual Race to Erase MS event on May 18, 2012. Teri, Deb and Bill have been instrumental in the support of the Nancy Davis Foundation for MS and have made a tremendous impact in the community by educating the public, raising awareness, and funding vitally important multiple sclerosis research. We look forward to honoring these three generous individuals who have been a tremendous inspiration and have made a significant impact, bringing us one step closer to finding a cure for multiple sclerosis. Visit www.erasems.org for more information on the event and full biographies on our honorees.



The MacMillan family, Deb, Bill, Cammy, Jim, Kiki, Bill Jr., and Alexis, have been a passionate and driving force in the battle to conquer Multiple Sclerosis. Their interest in the Race to Erase MS began with Deb's battle with fibromyalgia and her desire to find an organization that effectively funds research into curing auto-immune diseases. Soon after, she met Nancy Davis and learned about Nancy's great success in bringing experts together from

throughout the world to research cures for MS and, hopefully, other auto-immune disorders. The MacMillans quickly became devoted to the Race to Erase MS and The Center Without Walls program. The entire MacMillan family has become ardent supporters, serving on committees, donating auction items, making generous donations, and bringing dozens of guests to this wonderful and important event. During their many years of supporting the Race to Erase MS they've developed a highly increased awareness of the devastating effects multiple sclerosis has had on those who suffer from it but also the patients' loved ones. The MacMillans have been especially happy to be able to introduce several friends who struggle with MS to the wonderful work of the Race to Erase MS and The Center Without Wall program.



In October 2002, Teri announced on national television that she had multiple sclerosis, making headlines across the country. Since then, she has become a leading advocate in raising awareness for MS and the latest treatments for the disease, traveling around the United States speaking to corporations, physicians, and patients about her experience. She is an inspiration to every audience as she shares her journey with her symptoms of MS. People say that

because of her, their symptoms will no longer get in the way of their dreams. Teri has also served as member of the Board of Directors of the Nancy Davis Foundation since 2003 and is an inspiration to all of our supporters. Professionally, Teri Garr can claim a career in show business by birthright. She was born in Hollywood, the daughter of Edward Garr, a Broadway stage and film actor and Phyllis Garr, a dancer. While still an infant, her family moved from Hollywood to New Jersey. After the death of her father when she was eleven, her family returned to Hollywood where her mother became a wardrobe mistress for movies and television. Teri has starred in many memorable films including: "Young Frankenstein;" "Oh God!;" "Close Encounters of the Third Kind;" "Mr. Mom" and her Academy Award-nominated performance for Best Supporting Actress in "Tootsie".

We look forward to celebrating with everyone in May 2012, so make sure to mark your calendars! For more information call 310-440-4842.

Nancy Davis Foundation for Multiple Sclerosis

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Annual MS Forum and Expo May 9, 2011

David Osmond kicked off our annual MS Forum with an inspiring musical performance and talked about his own triumph over multiple sclerosis. Hosted by WebMD, the most stellar panel of MS research scientists from the Nancy Davis Center Without Walls program updated guests on recent advances in MS therapies and research that will lead us to a cure. Our guest panelists included country singer Clay Walker and actress Teri Garr who shared their personal experiences with MS and helped others thru their own journey with the disease. Additional panelists included some of our brilliant scientists Dr. Emmanuelle Waubant (UCSF), Dr. Howard Weiner (Harvard), Dr. Leslie Weiner (USC), Dr. Stephen Hauser (UCSF), Dr. Dennis Bourdette (OSHU), Dr. Daniel Pelletier (Yale), Dr. Adam Kaplin (Johns Hopkins), Nancy Davis, David Osmond, Claudia Curry Hill and Katie Brass.

Participants enjoyed resources available to them through our health and wellness EXPO prior to the forum and we thank all of our EXPO Partners for their valuable participation. We would also like to thank Hyatt Regency Century Plaza, FIJI water, POM Wonderful, Clementine's, and Harry & David for their invaluable donations to this very important educational opportunity.

This annual event is free and open to the public and attendees have the unique opportunity to ask questions and to speak directly to top MS neurologists from around the country. WebMD hosted clips from the forum as well as interviews with some of our Center Without Walls doctors. Make sure to visit WebMD.com or our website to view the podcast of this special forum and to obtain additional information. Next years event will take place On May 19, 2012 at the Hyatt Regency Century Plaza so make sure to save the date and spread the word about this amazing and inspirational event!



Nancy Davis with Nan Forte and Guests



Lynn Palmer, Claudia Curry Hill and Guests





MS Expo Partner

MS Expo Partner



MS Forum and Expo



Nancy Davis with Shemar Moore and Guests



Dr. Emmanuelle Waubant,



MS Expo Participants



David Osmond and Teri Garr



Back: Dr. Emmanuelle Waubant, Katie Brass, Dr. Howard Weiner, Dr. Leslie Weiner, Dr. Stephen Hauser, Dr. Dennis Bourdette Front: Dr. Daniel Pelletier, Claudia Curry Hill, David Osmond, Nancy Davis, Teri Garr, Clay Walker, Dr. Adam Kaplin

Save the Date!

2012 MS Forum & Expo Saturday, May 19th Hyatt Regency Century Plaza, Los Angeles

Free and Open to the Public! Spread the word. Location is the Hyatt Regency Century Plaza.

For more information on becoming a 2012 EXPO Partner or to attend the event call our office at 310-440-4842 or visit www.erasems.org.

Teri Garr

A legendary role model



As an actress, I have been faced with many challenges. Some small and some large. The most significant challenge that I have been faced with is living with MS. I was diagnosed with this (scum sucking pig of a disease) in the 80's. At the time, most doctors had absolutely no idea what was happening to me. I must have gone to 10 dif-

ferent doctors before one of them finally said, "I believe you have multiple sclerosis." Of course at this point, I was happy to hear anything come out of a doctors mouth, but now I "could" have a serious disease that is very unknown. My symptoms actually started to hit me when I was doing my daily run through the park. I lived in New York at the time, and I felt, what I would expect a stab in the leg would feel like, a horrid stabbing pain in my leg. Being in the shady part of Central Park, I thought to myself, "Oh God, here it is, I'm being mugged!" But I looked down and there wasn't a scary man in all black or knife sticking out of my leg, so I just brushed it off as a cramp. I then decided to see the doctor for the first time after this same sensation continued in my leg.

Most people come up to me and say, "my heart bleeds for you," or "you poor thing." Honestly, I don't need a pity party. I don't need someone to feel sorry for me. This disease has made me strong. Yes, at times I feel like my whole world is going to end when I can't open a jar of jam or I can't go for a jog or walk up a flight of stairs. But those are just small things that we, and when I say we, I mean the entire MS community can face. My daughter, Molly, one of the main reasons why I am so strong, always tells me, "Mom, you aren't sick, you are just especially different and incredibly awesome, and the most amazing mom I could ever ask for." She is why I can get up every morning and face the day like a champion. When you have MS, you are faced with hell. It will consume you and it won't let go. When it doesn't let go, you have to just find a way to become friends with it and make the best out of every situation. It's how I have faced the many challenges of multiple sclerosis.

Prevention Hero AwardsMarg Helgenberger honored for the Race

On June 21, 2011, Laura Petasnick, Publisher of Prevention, hosted the second annual "Prevention Honors Hollywood Heroes," an evening in celebration of remarkable women committed to making a world of difference.

Prevention honored Golden Globe nominee Marg Helgenberger on behalf of the Race to Erase MS along with Emmy and Tony Award-winner Kristin Chenoweth on behalf of Maddie's Corner, Holly Robinson Peete on behalf of HollyRod Foundation and Laura Ziskin on behalf of Stand Up 2 Cancer, for their remarkable commitment to philanthropic causes. Asics once again teamed with Prevention as the evening's presenting sponsor.



Nancy Davis, Marg Helgenberger, Diane Salvator, Editor-in-Chief of Prevention and Laura Petasnick, Prevention Publisher

"Prevention's mission is to empower women to live healthier, happier lives, everyday. Our 2011 Hollywood Heroes are truly awe-inspiring women who embody this message by using their star power to improve the lives of others. We're so honored to salute this amazing group," said Laura Petasnick, Publisher, Prevention.

The evening began with cocktails and hors d'oeuvres at the Sunset Tower Hotel, followed by an awards presentation spotlighting each of the honorees and her unique contribution to the world of philanthropy. We send out a heartfelt thanks to Marg Helgenberger and Prevention Magazine for their incredible support and recognition of our mission and our quest to find a cure for multiple sclerosis.

We are so grateful for the awareness that has been brought to the cause of MS through such an amazing evening honoring the most heroic women in philanthropy.

Falls and Imbalance in Multiple Sclerosis

Michelle H. Cameron, MD, PT, OSHU

Imbalance and falls are common, which is disabling and poorly understood problems for people with MS. Dr. Michelle Cameron's research is helping us understand why people with MS have such poor balance and why they fall so often. This research is essential for us to develop effective interventions to improve balance, prevent falls and maintain the independence of those living with MS today.

Studies show that more than 75% of people with MS have problems with their balance and that more than 50% fall at least once every 3 to 6 months. Problems with balance cause falls and make people afraid of falling. They can also cause injuries, limit activity, and stop people from living independently. Today, we know that imbalance and falls are common in people with MS and Dr. Cameron's research is helping us to understand why people with MS develop these problems and how to prevent them. At Oregon Health & Science University (OHSU), in collaboration with Dr. Dennis Bourdette, an MS expert, and Dr. Fay Horak, a balance expert, Dr. Cameron started to investigate the causes of imbalance in MS. She found, in a small group of people with MS and imbalance,

(FALLS continued on Page 9)

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photo gallery: 18th Annual Race to Erase MS



Clay and Jessica Walker



Nancy Davis, Ken Rickel, ABS Model, Mariella and Isabella Rickel



Jim MacMillan, Deb MacMillan, Drew Anderson, Kiki MacMillan



Cindy Crawford and Paris Hilton



David Osmond, Clay Walker,
Debbie Gibson, Nancy Davis, Mark Curry



Model in ABS "Kate" Wedding Gown



Bill Perkins (center) with Guests



Kathy and Rick Hilton



Dwight and Julie Opperman



Tawny and Jerry Sanders



Laura and David Mckenzie



Clementine Ford and Guest



Katie Leopold, Nan Forte, Susan Sweet, Nancy Davis, Steven Cojocaru



Paul and Lynn Palmer



Andy Hilfiger and Guests



Cynthia Burton, Luci Lawrence, Barbara Davis, Cindy Farber, Debbie Lustig



Molly O'Neil and Teri Garr



Matt Johnson, AJ and Katie Brass, Daphne and Ernest Scalamandre



Virginia Madsen and Garcelle Beauvais



Gray Peterson, Nancy Davis, Elizabeth Peterson



Anna Trebunskaya



Rickey Minor, Saeid Davoudi, Kathy Gohara, Karen Minor



Nancy Davis and Jimmy Lustig



Scott and Stephanie Cleveland



Bill Maher



Nancy Davis and Lynn Palmer



Marivi Garcia, Gerryann Agovino, Margarita Leon, Rose Fahey, Debbie Eaton, Silvia Baker and Sherry Corday



Isabella Rickel, Lindsay Schoenweiss, Mariella Rickel



Nicky Hilton



Kathy and Paris Hilton, Nancy and Barbara Davis, La Toya Jackson



Jack Rich and Debbie Gibson



Nancy Davis, Mark Burg and Shai Donnelly



Paris Hilton



Nicole and Mark Curry with Nancy Davis



Steve Ponce and Cammy MacMillan



Cheryl Burke and Louis Van Amstel



Kym Johnson



Andy Hilfiger and Band



Brandon and Nancy Davis



Jazzlyn Marae with Elizabeth Stanton



Nancy Davis, Jason Davis and Jason Wahler



Mary Milner, Lynn Palmer, Lauren King



Alexander Davis and Lindsay Schoenweiss



Alexis Berman, Alexander Sadof, Jordan Cohen, Sarah Smith



Claudia Curry Hill. David Osmond, Brandon Blain



Zoey Deutch, Lea Thompson, Nancy Davis



Stanley and Joyce Black



BG5 modeling in Andrew Charles Fashion Show



Paul Palmer, Jon Lovitz, Lynn Palmer, Barbara Davis



Lyndi Hirsch and Guest

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ms health tips and resources

The Power of Vitamin D

Women's Health magazine recently discussed the importance of Vita D and specifically mentioned how important it is for autoimmune diseases. According to Dr. Michael F. Holick, Ph.D., M.D., director of the Vitamin D, Skin, and Bone Research Laboratory at the Boston University School of Medicine, 600 IU a day, is still not enough for most men and women. Especially if you have immunesystem illnesses such as multiple sclerosis. In a new research, getting between 1,000 and 2,000 IU a day may help strengthen the immune system and could cut a woman's overall MS risk by 40 percent. With so many women D-deficient, increasing your levels could not only fight off immune-system diseases, but also depression, and even cancer says Sarfraz Zaidi, M.D., author of The Power of Vitamin D. In efforts to help women already suffering from MS, Jodie Burton, MD, a neurologist at the University of Toronto conducted a study for WebMD and found higher doses of Vita D dramatically cut the relapse rate as well. They found that taking a higher dose of Vita D women suffered 41 percent fewer relapses than the year before the study began, compared with 17 percent of those taking typical doses.

Our own Center Without Walls team at USC, lead by Dr. Leslie Weiner, is in the middle of an observational study looking at Vita D and its impact on disease disability by ethnic background. The project is spearheaded by Dr. Lilyana Amezcua with a focus right now on caucasian compared to hispanics. The deficiency in certain populations may represent different sun light and dietary needs which they hope to answer. Their recommendation is to consult your doctor and have your Vita D assessed before the start of replacement. An individual with a level below 10ng/ml will require much higher supplementation. The good news is that Vita D can likely impact disease activity in MS and is showing to be a positive outlook for a longer life.

Unique Technology Rapidly Removes Heat

In research funded in part by DARPA, scientists learned that by applying a carefully controlled lower temperature to the palms of the hands and soles of the feet, they could augment the body's naturalcooling process and speed it up 3 times or more! The result of this discovery is $CoreControl^{TM}$ by $AVAcore^{TM}$ Technologies, Inc. The hand fits inside a battery powered device about the size of a coffee pot and grips a metal cone with circulating cool water. The water is cooled by ice. The device closes around the wrist and a mild vacuum is applied. Multiple laboratory studies have confirmed that accelerated cooling occurs returning the body to normal much faster. Users of CoreControlTM do not experience cooler skin or that feeling you get from jumping into a pool. Rather they stop sweating and report feeling refreshed and ready to do more work. They are cooling from the inside out. For more information on this technolgy visit avacore.com.

Help for Foot Drop and Hand Paralysis

The NESS L300 Foot Drop System from Bioness is a medical device that helps certain individuals walk with increased speed and improved balance - allowing you to regain your freedom and independence. It uses low-level electrical stimulation to activate the nerves which control the muscles to lift the foot. The system has three wireless components that adapt to changes in walking speed and terrain, allowing you to walk easily over stairs, grass and carpet. The NESS H200 Hand Rehabilitation System from Bioness activate the various muscle groups in the hand and forearm allowing you to open and close your hand. The H200 is intended to provide certain individuals with hand paralysis the ability to grasp and release objects while performing ordinary and essential activities of daily living. For more information visit www.bioness.com.

Tips when Traveling

Below is a summary of the accessibility advice provided by <u>accessibledenver.com</u> published by Cindy Christensen as well as some advice from our own supporters. For more tips check out Cindy's website.

Booking your Flight: Whether using a travel agent or a travel website, make sure to look for a request box that allows you to express your individual needs like wheelchair accessibility or needing additional assistance. Make sure to tell your travel or booking agent. Medications: If traveling with injections, make sure to have a doctors note or call ahead to confirm proper protocol for traveling with liquids or therapies that require refrigeration. Airport Wheelchair Service: If using a wheelchair service of an airline, they typically do not allow anyone else to push the chair except for their designated staff. You should check to make sure the service will take you all the way to the gate for boarding. You can also look into purchasing an ultra light wheel chair for easy travel with companions that may be traveling with you. Security CheckPoint: Call ahead to find out what the accessibility guidelines are for your terminal and airline carrier. Also check to see if your travel companion can go with you or you should expect to be separated as you go through security. You should also expect TSA to scan not only yourself and your carry-ons, but your wheelchair or any other devices that you require to assist you in your travels. Boarding: If you can board the airplane, your wheelchair will be tagged and checked at gate. If you are utilizing a wheelchair service, they should be waiting for you at your destination when you land. If you must check your wheelchair, make sure to ask the carrier if it will be brought back to you at the gate or if you will need wheelchair service in order to retrieve your chair at baggage claim. It is important to make a list for yourself when you travel of any of your needs so you can properly ask questions to ensure you travel is easy and comfortable.

Treating Chronic Pain

Stimulators have been used extensively to treat chronic pain. Fishger Wallace is just one type of stimulator. They work for many, but not all patients. They provide some relief from chronic pain of many types, though according to research sources, the exact mechanism of how they work is not known. The Fisher Wallace Stimulator is a portable, battery-powered, pulse generator that has been cleared by the FDA for symptomatic relief of chronic pain. It delivers a micro-electrical stimulus that is carried by electrical cables to wet sponges (supplied with the device) which are applied to the skin. The electrodes may be placed on the head to stimulate endorphin release to treat chronic pain associated with MS and other generalized chronic pain conditions, for more information visit www.fisherwallace.com.

(FALLS continued from Page 5)

that for most of them, the underlying issue appeared to be difficulty feeling a connection to their feet quickly enough to maintain their balance. Dr. Cameron then investigated if people with MS really fall more than people without MS. She found, in her study of Veterans, that those with MS had a two to three times higher risk of a fall resulting in injury than those without MS.

Dr. Cameron is now carrying out a larger study to more fully understand the mechanisms underlying imbalance and falls in MS - is it all a problem with feeling where your feet are or is there more to it? She is also examining how balance in people with MS changes over time, in part to see if balance can be used as a measure of MS disease progression. In addition, she is going to study the effects of targeted treatments, such as dalfampridine (Ampyra®) and specific physical therapy interventions, for imbalance and falls in people with MS. This research has the potential to vastly improve the quality of life and prolong the independence of people living with MS today.

Coping with Depression and MS

Dr. Adam Kaplin and Kristen Rahn, Johns Hopkins

Mounting evidence suggests that depression in multiple Sclerosis (MS) is immune-mediated and the result of brain inflammation rather than the patient's environmental situation. Trouble with concentration and memory, though often subtle to other people, is a frequent and distressing effect of MS. The recognition of MS-related cognitive deficits has dramatically increased in recent years, with the average proportion of MS patients recognized to have cognitive impairment increasing from 3% in the 1970s to approximately 50% today. This would suggest that the management of depression is an integral part of the general treatment of MS, entirely similar to the treatment of other disease-related disabilities involving motor, sensory, and autonomic dysfunction, with potential prognostic implications for the overall course of the disease progression. Recognizing depression in MS patients, however, can be challenging because of the overlap of symptoms between psychiatric and neurologic illnesses. For example, fatigue, cognitive impairment, poor appetite and insomnia occur in many non-depressed MS patients, making reliance on these symptoms difficult in making a diagnosis of depression.

The social and financial burdens of cognitive impairment in MS are also staggering. The average age at the time of MS diagnosis is 20 - 40 years of age, and approximately 70-80% of MS patients are unemployed within 5 years of diagnosis. Despite the frequency of concentration and memory difficulties caused by MS and their negative effect on quality of life, no therapies have been developed to treat them. In an attempt to provide therapies, human data collected at Johns Hopkins Hospital established that MS patients have a 50% decrease in the concentration of a unique and poorly understood peptide called NAAG in the hippocampus, an area of the brain responsible for learning and memory, compared to healthy controls. This decrease in NAAG in MS patients correlated with the severity of their memory and concentration problems, and conversely the higher the NAAG levels the better their cognition. Based on these data, we hypothesized that increasing NAAG concentration could provide a unique and novel therapy for treating cognitive impairment in MS and other disorders of the CNS. Using a mouse model of MS and behavior tests evaluating cognition, we measured learning and memory performance following chronic treatment with a drug that increases NAAG levels in the brain. While this drug treatment had no effect on the physical activity of the mice, the drug selectively improved the memory and learning of treated mice thereby allowing them, for example, to run through mazes 40-70% better than their untreated siblings. Based on these data, we consider increasing NAAG concentration in the brain to be a novel treatment strategy that may allow us to prevent and treat cognitive impairment in those affected with MS.

The importance of making the appropriate and timely diagnosis of depression in MS patients is critical. Often what is most debilitating is not the need for assistance with walking or adaptations to disability, but the depression that leads to difficulty getting out of bed, social isolation, and lowered pain tolerance. Patients and doctors should be aware of classic symptoms of depression, such as hopelessness and loss of interest or motivation, commonly construed as "giving up" rather than interpreted as symptoms of an illness that needs to be treated. Patients also tend to feel that seeking treatment for depression means they are crazy and so avoid seeking evaluation and treatment for fear of being stigmatized. Fortunately, depression is one of the most treatable symptoms of MS, as long as patients aggressively treat this symptom as they would in managing other aspects of their disease such as injecting therapies to curb inflammation or physical therapy and rehabilitation to enhance motor function. Depression can be adequately treated, but it must be properly recognized and diagnosed before it can be comprehensively managed. It is important to address any symptoms with your doctor.

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highlights from the lab

Center Without Walls Program Young Investigator Research Update

Our mission is to fund cutting-edge, innovative research programs in our quest to find a cure for multiple sclerosis. We are thrilled to support the best and the brightest young minds in scientific research. Below are annual updates from our second year Young Investigator grant awardees that began their basic science research in 2010 as well as research study summaries from our newly awarded 2011-2012 Young Investigators and Pilot Studies.

Young Investigator (YI) Summaries: Support for a promising new investigator performing state-of-the-art MS research.

2nd Year YI Grant Recipients

Kevin C. O'Connor, PhD Assistant Professor of Neurology Yale School of Medicine



Antigen-antibody complexes in MS: Much of the tissue damage that occurs in the MS brain and spinal cord is led by the immune system. Among the cells partici-

pating in this assault are B cells. B cells have receptors (antibodies) on their surfaces, which bind to proteins and other biological components. B cells recognize these components (termed antigens) as foreign (non-self) through the binding of the antibodies on their surface. This binding stimulates the B cell to begin secreting those antibodies that then bind antigens marking them for immune mediated destruction. When this occurs to self, rather than foreign, antigens B cell autoimmunity is occurring. This process may be occurring in MS central nervous system (CNS) lesions, but many of the details remain unknown. Our group recently determined that the MS CNS harbors a related network of B cells and secreted antibodies. We have put forth an effort to identify the antigen(s) that these B cells recognize and several candidate antigens have been identified. In our current work we are evaluating if these newly identified antibody-antigen pairs can be found in the cerebrospinal fluid

and blood of these/other MS patients. If they are, we will correlate their presence with clinical parameters in an effort to identify new biomarkers for MS. We are equally focused on understanding the role these antibodies play in the destruction of tissue in the MS CNS. Recently, we have begun developing a program to examine the role of commensal microbiota in MS CNS inflammation and developing a model to study how B cells present antigens to T cells. The overall study aim is to provide insight into the nature of the autoimmune B cell's response in MS. This work is meant to understand the immunopathology of MS and may lead to novel approaches in disease prevention or treatment.

H.-Christian von Büdingen, MD Assistant Professor of Neurology University of California, SF



The role of antibodies in MS: Several lines of strong evidence ascribe antibodies an important role in the formation of scars in brain tissue of MS patients. This

research project will, therefore, study the influence of MS antibodies on induced pluripotent stem (iPS) cell-derived brain cells from MS patients. iPS cells can be derived from adult skin cells; to date, we have obtained iPS cell lines from 3 patients with MS. The overall goal is to unequivocally establish the disease-relevant role played by antibodies in MS. Such knowledge is expected to greatly enhance our understanding of MS and will likely facilitate the development of innovative therapies.

Jack Ratchford, MD Assistant Professor of Neurology



Johns Hopkins University

Optical coherence tomography is a biomarker of axonal integrity in MS:

Though MS treatment

has advanced greatly, identification of neuroprotective treatments strategies remains a very important goal of MS research. Testing of potential neuroprotectants has been limited by the difficulty of measuring neuroprotection well. Optical coherence tomography (OCT) is a non-invasive imaging technology that allows us to precisely measure the health of the nerves in the back of the eye. We expect that in the future, OCT scanning will help us test potential neuroprotective compounds in MS.

To learn more about using OCT in MS we have several ongoing studies. In one study we are learning about the link between OCT and MRI in MS by following 100 MS patients with periodic OCT and MRI scans for two years. We are also using OCT to follow a group of patients who have had optic neuritis (an MS attack affecting the eye). This study has given us some novel insights about how the retina changes during and after optic neuritis. We hope to use these insights to design clinical trials that will test neuroprotective medications in patients who have an optic neuritis attack. The support of the Nancy Davis Foundation has greatly helped our quest to advance knowledge about this promising approach.

1st Year YI Grant Recipients

Lilyana Amezcua, MD USC Keck School of Medicine



Exploring the influence of ancestry in MS characteristics:

Multiple Sclerosis (MS) is traditionally thought to affect whites of European background

and emerging evidence shows that more cases of MS is rising among certain populations where MS is thought to be less common, such as Hispanic/Latino Americans. In addition, MS shows differences in presentation and course between European whites and individuals of Asian, African American, and Hispanic/Latino background. We at USC that Hispanic/Latino have found Americans have a mixture of European and Asian traits in the way their MS behaves. They develop MS at a much younger age and have a higher propensity to present with more visual and spinal cord attacks, typical of an Asian form of MS known as opticospinal MS (OSMS).

Relying on the genetic ancestral substructure in the Hispanic/Latino, who is a European derived population, we would like to examine genetic clues linked to geographical origins that may be responsible for their clinical variability. We will recruit 300 individuals of Hispanic/Latino background and identify genetic patterns of ancestry associated with the OSMS, and classical MS. This study has the potential to identify factors associated with treatment failure, to predict clinical outcomes associated with specific ancestral genes, and contribute to our overall understanding of MS in all populations by identifying novel genes associated with specific characteristics of clinical disease. The support of the Nancy Davis Foundation will help us translate this information into the next step forward, that of personalized medicine.

Eve Kelland, Ph.D. USC Keck School of Medicine



The role of the inflammatory mediator CXCL8 and its receptor CXCR1 on human brain stem cell function and repair in MS: In the earlier stages of MS the body is able to

repair some of the damage caused by the immune system using the body's own source of stem cells. Adult neural stem cells (NSC) and their specific daughter cells, oligodendrocyte progenitor cells (OPC), reside in the brain and during an MS attack can be recruited to the site of injury and repair the damaged central nervous system. However as the disease progresses this stem cell pool is unable to keep up with the damage and stem cells that are recruited to lesion sites often fail to become fully functioning replacement cells. It is not clearly understood why the stem cells fail but evidence suggests a role for inflammatory molecules. These inflammatory factors, along with their specific receptors can influence the function of cells in the central nervous system both positively and negatively.

Our research group has demonstrated an increase in the levels of a specific immune molecule, CXCL8, in patients with MS. This immune molecule has preference for the receptor CXCR1, whose increased expression has also been demonstrated in active lesion sites from MS brains. Using human NSC and OPC cultured in our laboratory it is our aim to determine whether activation of the CXCR1 receptor critically affects functions of NSC and OPC needed for repair, and if so, how it works. The support of the Nancy Davis Foundation will help define the role of inflammation in NSC and OPC repair, improving our knowledge of MS and opening new doors for future treatment strategies designed to target repair of the central nervous system.

Murugaiyan, Gopal,PH.D. Brigham and Women's Hospital



Investigation of IL-27 on Th9 cells in MS: Multiple Sclerosis (MS) is a complex genetic disease characterized by inflammation in the central nervous system

white matter mediated by autoreactive T lymphocytes. The development of T lymphocyte subsets is orchestrated by cytokines produced by dendritic cells (DCs). Among the CD4+ T cells, CD4+CD25+Foxp3+ Tregs and T regulatory type 1 (Tr1) cells are instrumental in the prevention of tissue inflammation and autoimmunity. Contrary to regulatory T cells, T helper1 (Th1) and T helper 17 (Th17) and Th9 cells known to have potent pro-inflammatory functions and promote autoimmunity. The role of DC function in MS and how it relates to adaptive immune responses in the disease is not well understood. IL-27 is a member of IL-12 family cytokine produced mainly by antigen presenting cells such as DCs. The primary objective of our work is to understand the role of DC produced IL-27 in the regulation of inflammatory and regulatory T cells in patients with MS and its animal model experimental autoimmune encephalomyelitis (EAE). Thus the overall study will greatly enhance our understanding of the immunology of MS and lead to effective ways to treat the disease.



Multiple Sclerosis Symptoms: Most common early symptoms of MS include: Loss of balance, Weakness in one or more limbs, Blurred or double vision. Less common symptoms of MS may include: Slurred speech, Sudden onset of paralysis, Lack of coordination, Cognitive difficulties.

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highlights from the lab, new grant receipents continued

Pilot Study Summaries 2011-2012: Support for a focused research project that is novel and will unravel new aspects of MS.

Emmanuelle Waubant, MD, PhD Associate Professor of Neurology Dir., Regional Pediatric MS Center UCSF



Pediatric MS: Waubant's specific interests include the translation of promising MS drugs from the bench to the bedside, understanding factors that predict the response

to MS therapies, and risk factors for pediatric MS susceptibility and disease modification.

As such, she has found that some viruses acquired in childhood may increase or decrease the risk to develop pediatric MS, sometimes in the context of one's genetic background. She has also found that low levels of vitamin D in the blood is associated with a higher risk of MS relapse in patients with an established disease. Her findings have resulted in developing a trial of vitamin D supplementation in MS that will start during the 3rd quarter of 2011.

With the specific project supported by the Nancy Davis Foundation, Dr Waubant will study whether children with MS have different germs in their guts than children who do not have MS. This study is based on the concept that the mix of microbes the gut is determined at a very young age and influences the way the immune system develops. Thus, various gut microbes may increase or decrease the risk of an individual to develop an autoimmune disease such as MS. Identifying these differences may help understand better why MS develops. This could ultimately lead in preventative strategies to decrease MS risk.

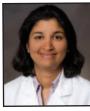
Peter A. Calabresi, MD Professor of Neurology Dir., Johns Hopkins MS Center Dir., Division of Neuroimmunology and Neuroinfectious Diseases



Thyroid hormones induce remyelination:
It has been known for years that thyroid hormones are critical for the normal development of myelin in fetuses and

babies, but the role of thyroid hormones in adults has not been extensively investigated. We have found that adult human and rodent precursor cells in the brain can be driven to become myelinating cells (oligodendrocytes) using T3, a common thyroid hormone. Too much T3 can be toxic to the heart by overstimulating receptors on the heart tissues, but thyroid hormone analogues (mimics) that stimulate a different receptor found on the liver are being studied by other groups because they seem to promote weight loss and lower cholesterol levels. We discovered that one of these thyroid hormone analogues called GC1 promotes myelin forming cells as well or better than T3 in tissue culture because the alternative receptor is also expressed on the precursor cells in the brain. We are now testing this compound in an animal model of demyelination to determine if it can promote remyelination. The support of the Nancy Davis Foundation is greatly helping us to rapidly translate this laboratory finding into a novel reparative therapy for MS patients.

Vijayshree Yadav, MD, MCR Clinical Dir., MS Center of Oregon, Assist. Professor Of Neurology, OHSU



Oral lipoic acid as a treatment for acute optic neuritis: Acute optic neuritis (AON) is a common manifestation of clinical relapse in multiple sclerosis (MS) and

often the initial clinical event of MS. AON remains one of the most frequent inflammatory causes of visual disability among young and middle-aged adults.

While most patients with AON experience significant recovery of vision, many have some residual, visual symptoms, and most have evidence of permanent damage to their optic nerves. The only treatment for AON is high dose steroids given intravenously. This treatment speeds up recovery from AON, but does not affect the long-term outcome of vision recovery and can cause significant side-effects. There is, therefore, a need to develop a nonsteroidal treatment for AON that is welltolerated and decreases permanent injury of the optic nerve. One possible treatment to reduce visual impairment in AON is the anti-oxidant, lipoic acid. Encouraging initial clinical studies led us to hypothesize that lipoic acid will be an effective therapy to reduce inflammation in the optic nerve, reduce nerve damage, and improve visual outcome in people with AON. To test our hypothesis, we will conduct a 24-week, randomized, placebocontrolled, pilot trial to study the effects of oral lipoic acid on nerve fibers in the affected eye of AON subjects. The results of this pilot trial will provide a rationale and preliminary data to design a larger clinical trial to prove whether oral lipoic acid can be used as an effective treatment for AON. If we are able to show that oral lipoic acid works for AON and is a safe treatment, the results can be extended to treatment of MS relapses. If research results are promising, it will be a huge step forward in the acute treatment options for AON and MS relapses.

Wendy Gilmore, Ph.D. and Michael Kahn, Ph.D. USC Keck School of Medicine



Promotion of CNS repair via modulation of Wnt signaling using small molecule modulators: The Nancy Davis Foundation will support a pilot project developed

by Dr. Wendy Gilmore at USC, in collaboration with USC biochemist Dr. Michael Kahn. Many of the currently available drugs for the treatment of MS are effective because they control immune

highlights from the lab

responses that initiate damage in the brain, spinal cord or optic nerves (the central nervous system, or CNS). However, none of these drugs are able to directly overcome blocks to repair processes that occur in MS that often lead to disease persistence and progression. New information indicates that neural (brain) stem cells receive abnormal signals via a pathway known as the "Wnt" pathway, blocking their ability to repair damage to myelin and axons in MS. In this pilot study, Dr. Gilmore wishes to test the potential for a new experimental drug, known as ICG-001, developed by Dr. Kahn, to correct these abnormal "Wnt" signals and allow repair to take place.

Dr. Kahn has proven that ICG-001 promotes repair and clinical outcomes in a variety of disease models, but Dr. Gilmore is the first to test it in models of MS. Preliminary data are encouraging, and justify the effort to conduct additional studies that are necessary before considering it as a candidate for treatment in patients with MS. In addition, a form of ICG-001, known as PRI-724, is currently being tested in a phase I clinical trial to establish safety parameters in patients with gastrointestinal cancer. Thus, if this trial and our pilot project are successful, there is potential to apply PRI-724 for testing in a phase I clinical trial in MS patients. The support of the Nancy Davis Foundation is essential to establishing whether correction of abnormal "Wnt" signals can release the blocks to repair and provide a new approach to the MS treatment.



Center Without Walls Update:

Rsearch that has been previous funded and is still ongoing through our program:

The Center Without Walls was very active in 2010-2011, accomplishing many research projects. The group at the University of California San Francisco has moved forward with identification of new genes that increase MS risk, and also identified new relationships between genes and MRI measures.

Yale demonstrated that important communication channels between brain cells are expressed differently in MS lesions and normal brain, explaining why transmission of nerve information can be altered in patients with the disease. Harvard made new observations in terms of insight on the effect of the drug called Tysabri on the immune system and has tested in humans a promising new drug called oral anti-CD3. Also, Harvard has investigated factors associated with treatment failure.

Johns Hopkins has worked towards understanding how MS causes clinical depression and cognitive impairment and has also studied a combination of antidepressants as potential drugs to protect brain cells.

The University of Southern California has continued their work with stem cells and their ability to help brain repair and regeneration. In addition, they have also advanced our understanding of the role of viruses in MS.

Oregon Health and Science University has studied on how to block a protein in mitochondria, the energy factories in cells, to protect nerve fibers and has shown how inflammation can disrupt the transport of proteins in nerve cells.

Finally, they have continued to evaluate lipoic acid as a promising treatment for MS.

Center Without Walls Collaborating Physicians

Dr. Lilyana Amezcua, University of Southern California Dr. Rob Bakshi, Harvard Brigham & Women's Hospital Dr. Dennis Bourdette, Oregon Health Sciences Dr. Peter Calabresi, Johns Hopkins Dr. Michelle Cameron, Oregon Health Sciences Dr. Tanuja Chitnis, Brigham & Women's Hospital Dr. George Eisenbarth, University of Colorado, Health Sciences Center Dr. Roopali Gandhi, Brigham & Women's Hospital Dr. Wendy Gilmore, University of Southern California Dr. Ari Green, University of California, SF Dr. Charles Guttman, Harvard Brigham & Women's Hospital Dr. David Hafler, Yale University Dr. Halina Hoffner, Oregon Health Sciences Dr. Adam Kaplin, Johns Hopkins Dr. Samia Khoury, Harvard Brigham & Women's Hospital Dr. Jeff Kocsis, Yale University Dr. Brett Lund, University of Southern California Dr Henry McFarland, Bethesda, NIH Dr. Luanne Metz, University of Calgary Dr. Ellen Mowry, University of California, SF Dr. Kevin O'Connor, Yale University Dr. Jorge Oksenberg, University of California, SF Dr. Daniel Pelletier, Yale University Dr. Scott Zamvil,

University of California, SF

photo gallery, continued

Race to Erase MS



Sugar Ray Leonard, Nancy Davis and Bernadette Leonard



Nancy Davis, Jason Kennedy and Bruce Perlmutter



Daniel Gillies and Rachael Leigh Cook



Lynn Palmer, Nancy Davis, Jan Miller and Julie Chrystyn Opperman



Janice Dickinson and Guest



Erika Garcia-Lavyne and Guest



La Toya Jackson



Jessica and Clay Walker and Guests



Stephanie Cockrell, Brooke Wilbratt, Katie Brass, Jessica Jacobe



Melissa Joan Hart



Nancy Davis with Deb, Cammy and Bill MacMillan Jr.



Shaun Robinson and Mark Curry



Raven Symone



Tia Carrere and Nancy Davis



Hallie Brass, Skye Perkins, Joycie Brass Johnathan Bash





Pam McMahon and Guests



John Esteves and Chris Timpanelli



Anne and Frank Johnson, and Joni Flax



Byron Allen, Nancy Davis and Jennifer Lucas



Meg Tilly and Guest



Chelsea Kane and Stephen Colletti



Adam Mattingly, Stephanie Cockrell, Brian Hendry



AJ Michalka



Howard Levine, Joan Elledge, John Cruz, Pam Levine



Dennis Ventry, Michelle Kaplan, Michael Fields, Jill Mahmarian, Josh Kaplan



Marcy Taub and Nancy Davis



Richard David, Nancy Davis, and Mark Held



Drake Bell and Guest



Lynn Palmer, Nancy Davis, Ken Rickel, Kathy and Rick Hilton



Bill Perkins, Katie Brass and Dr. Stephen Hauser



David Faustino and Guest



Regina King



Dina Cohen, Evelyn Rickel, Noel Cohen, Bob Rickel



Nancy Davis



Jamie and Austin Winkler



Cindy Locke, Mary Ellen Mitchell, Addie Martini, Nicole Whitmore



Ryan and Carmel Giese



Stephanie Perkins and Nancy Davis



Kurt Knutsson, Maggie Knutsson, Matt Rosler, Todd Lieberman, Heather Lieberman



Clay Walker



Paris Sanders with Guest



Tye Strickland, Melissa Rycroft and Mike Catherwood



Samantha Harris



Toni and Don Hudgins, Diana Mattingly, Lou Anne Kellman, Katie Brass



Joan Jett



David Horowitz and Guests



Deb MacMillan, Nancy Davis and Connie Genova



Guests with Dr. Dennis Bourdette, Dr. Emmanuelle Waubant, Dr. Adam Kaplin



Daisy Fuentes



Dr. Drew Ordon and Dr. Lisa Masterson



Heather Ackroyd, Gordon Holmes and Laura Wegner

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inspring words from our supporters

Journey of Hope

By Cindy Locke



Cindy and Carrina Locke

Let me start with the usual pleasantries. My name is Cindy Locke and I am a 40 year old mother of two beautiful children, 5-year old Carina Hope and our little 9-month old son, Joshua. In August of 2006 we were in Germany for our little girls christening and my left leg, from the calf down to my foot, went numb. I just shook it off as possibly a pinched nerve from carrying Carina around for 4 hours straight each day. When we arrived back home my right leg started to feel numb, then my face, and soon after, my tongue. I did a bit of research on the internet before my doctor's appointment and knew that MS was for sure a front-runner of what was wrong with me. Along with being numb, I was forgetting things and not able to find my words. Being a writer at the time, it was very noticeable to me and "forgetting" was one of the MS

symptoms I had read about.

The doctor ordered a MRI and called us a few days later after the results and told me to come in and "bring your husband with you." Panic-stricken, we finally got the results. I have MS. The first thing we thought was, "Well, at least it isn't a blood clot in the brain...it's only MS." Little did we know that our lives would forever be changed and the word "only" would prove to be ridiculous. Within a few months, I went from being the life of the party and a fun, loving wife, sister, daughter, mommy and boss, to being an angry and generally not-nice-to-be-around person. I was very sick and could barely use my hands. My husband, daughter, mother and brothers were all I could think about, not myself. I couldn't imagine what their life was going to be with me... What kind of mommy could I be?

Then I read "Lean on Me" by Nancy Davis and found inspiration and hope. I focused on the fact that she was a mother of small children when she was diagnosed and went on to get a black belt in Karate! I was so impressed by what the foundation was doing that I contacted them to see if I could donate proceeds of our product to help them find a cure. Nancy Davis, and Liz Seares at the foundation, welcomed me with open arms and made me feel like one day, I might be able to be the mommy that I had always hoped to be.

Four years later, I am feeling as okay, as best as those of us with MS could feel. My business is still thriving and I am still actively involved. Through this journey, it took me 4 years to decide to have another baby and I am SO glad that I did. Our little Joshua is such a joy and our little Carina Hope is the sweetest, most helpful little girl. She knows when I don't feel well and does her best to help me with things. I still don't know how to explain MS to her, mostly because I don't understand it myself! It's different every day.

Even though my MS has leveled out for now, I am still different than I was before, dizzy, weak and still a grouchy-grump on some days. Yes, I still wonder each night when I go to sleep that something may possibly not work in the morning, but I am grateful to have a very supportive husband and family and know that isn't something to take for granted. I start each day saying to myself, "Do not let what you cannot do interfere with what you can do!"

Breaking Silence By Julie Huddleston

Julie Huddleston, from Ohio, generously raised money for our "Orange You Happy to Erase MS" campiagn this past May. We thank her for her invaluable comtributions to the cause, congratulate her on her strength and thank her for letting us share with others her journey with breaking the silence about her diagnosis. Below is an excerpt from her letter she sent to us. Thank you Julie!

Dear Nancy Davis Foundation:

Finding out that the strange symptoms that had been plaguing me for nearly two years were actually due to Multiple Sclerosis was not any easy thing. Finding it out two months after I opened a restaurant in Wapakoneta, Ohio made it even harder. Perhaps the hardest part, aside from conquering my fear of needles with daily injections, was attempting to avoid and deflect all the questions that I would get from patrons of the restaurant. No longer satisfied with telling them that my back was hurting, the constant badgering became a lot to handle, especially while I was trying to work. It became clear that I was going to have to go public with my disease, but I spent weeks attempting to come up with a way to put an end to all the questions, but not put the spotlight squarely on me.

About this same time, my daughter had found out about the Nancy Davis Foundation for Multiple Sclerosis and Orange You Happy to Erase MS May Campaign. We talked about it and decided that doing a fundraiser at my restaurant, Marley's Downtown, for a week in May would be a great way to not only raise awareness and funds about MS, but also allow me to announce my diagnosis as well. Eventually, you stop feeling sorry for just yourself and begin to feel the burden of every individual with MS and their struggles and you decide that it is imperative to do something about it, and that's exactly what we did.

During the final week before our fundraiser, I sent an e-mail to our customers reminding them that a portion of our food and drink sales were going to benefit MS research and education and that everyone should stop by Marley's Downtown to enjoy a great meal and help out an even greater cause. We also had one of our food sales representatives go above and beyond and donate an entire case of sirloin steaks for us to sell, which we paired with Bistro Potatoes called the Marley's Sirloin (MS) Special. They sold like hotcakes and we were able to really boost our fundraising numbers thanks to his generosity.

I won't lie; this week was a difficult week for me to get through. But every time it felt overwhelming, I reminded myself that I was giving back and hopefully my small part will help find a cure for MS. The event also helped to quiet the whispers that happened every time it took me a little longer to walk from the back of the restaurant to the front and even allowed me to meet and have discussions with other individuals that have MS in the area, which has really helped. I was very proud of my staff for stepping up and helping get the word out about the event and to everyone who did a little extra, whether it be a personal donation, a free box of steaks, or eating at Marley's Downtown multiple times during our fundraising week. I am very happy to be able to send you this check due to everyone's hard work and thoughtfulness and I hope that Marley's Downtown will be able to continue to make this May fundraiser a tradition at our establishment! Thank you for all that you do!



Julie and Ashley Huddleston

Our FaceBook Community

Inspiring stories from our followers

We recently posted a contest for our Facebook community to share their personal stories of triumph entitled "I Have MS, MS Does Not Have Me!" We asked our community to submit 350 words or less to share inspirational words of how they have conquered multiple sclerosis and stayed positive - in essence how one may have MS, but MS does not have you! Below are the top three stories chosen by our Facebook community. Thank you to all of our entries and for the amazing journey's shared by everyone!

"I Have MS, MS Does Not Have Me"

My name is Jessica Riddle. I have been living with MS since July 2004. When I was first diagnosed, it took me a complete vear to be able to admit I had it without breaking down into tears. I think part of the reason I cried was because I was scared of the unknown. I didn't know how having MS would affect the rest of my life. But, with the help of my wonderful doctor and the great support system I have in my family and friends, I am now able to go through life with a more positive outlook. As a result, I am involved with our local MS Society Chapter and this year, I participated in my very first walk. I have overcome a lot of obstacles and while living with MS is hard, I can say without a question of a doubt that I may have MS but MS will never have me.

Jessica, Akron, Oh, Age 37

"Dealing with the Hand I was Dealt"

My name is Ashley and I was diagnosed with MS at the age of 15. In the beginning I asked why me and then I realized God only gives you what you can handle and he must have complete faith in the fact that I could handle this disease. I speak about MS to my peers and educate those who have no idea what MS can do to ones body. I have spoken at several functions for different MS Societies to let people know that you can be any age and have MS. Being the age I was I felt it necessary to let people know that even though I look good on the outside, inside my body was

being invaded by a disease that not many know of. I love to tell my story so that if it could help one person see those with a disease or illness differently then I have succeeded in my task. I keep a positive attitude and share my story when I can. I will not let MS make me hide behind it, I will fight it with all my ability and continue to fight for a cure. To date I have raised over \$90,000 for research by walking and also hosting personal fundraisers. My MS will not take over my body, I am a fighter and will continue this fight till there is a cure found. That is why my favorite quote is, "Life is like a deck of cards, deal with the hand you are dealt!"And that is what I intend to do.

Ashley, Greensburg, PA, Age 20

"30 Year Old Mother & Wife"

My name is Amanda West. I am a married, 30 year old mother to a 1 ½ year old. October 11th, 2010 I woke to the 3 outside fingers on my left hand being numb. Over the next couple days my entire left side went numb. I really wasn't that worried – after all, I wasn't in any pain. Not to mention, I have been to the doctors for different issues for over 15 years & they've never found a cause. My doctor was worried though & ordered an MRI. I found out I have lesions on my brain & C5/C6 of my spine and on December 7th, 2010 after a spinal tap, I was diagnosed with MS. My husband & family was devastated. Me? I don't have time to be devastated. I have a husband & a baby to take care of. I immediately got online & did a lot of research. In the process I registered TEAM AMANDA for the 2011 MS Walk in Kalamazoo, Michigan. TEAM AMAN-DA walked on May 7th, 2011 with over 40 walkers & having raised almost \$5000!!! There isn't much I can do to stop this disease from overtaking me so all I can do is stay positive & raise as much money as I can for this cause. I have MS but it will NEVER have me!!

Amanda, Portage, MI, Age 31

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A Work of Heart

by Liza Levenson, M.Ed.



Kids at dreamMakerS

When I was younger, I dreamed of having the perfect first day of school outfit and more than one line in the school play. Let's just say that I learned there is no such thing as perfection and there are no small parts, only small actors! As I got older, my dreams matured as well. I dreamed my dad would be able to walk upstairs to kiss me goodnight, run alongside my bike after taking the training wheels off, and be healthy enough to attend my high school graduation. As you get older, other things change too when you have a parent with multiple scle-

rosis (MS). You start to notice if restaurants have ramps or just stairs, if people without the required handicap tags are parked in the spaces reserved for handicapped persons, if someone needs a door opened for them, or an arm to hold onto crossing the street.

dreamMakerS started as just that, a dream, as I was sitting around at dinner with my family in October 2010. As anyone who lives with someone with a chronic illness can attest, it can often feel as though everyone in the family has the illness, not just the person with the diagnosis. After my dad was diagnosed nine years ago, he and my mom attended a number of support groups and programs for people with MS and their spouses; however, there was nowhere for my brothers and me to turn to get information, support, or to talk about having a parent with MS with other children who could relate. Feeling helpless quickly led to feeling hopeless, and I never want another child of a parent with MS to feel that way. I wondered, what if there was a place for kids like my brothers and me, kids whose parents wanted to play catch with them in the backyard, but for whom the hill was too unsteady and the sun was too hot. What if there was a comfortable place where kids like us could get together, talk about our experiences and have fun? Children of parents with MS need a place of their own where it's okay that mom has to take a nap every afternoon, or dad has to use a scooter to attend class parties. A place where everyone knows how it feels to see your parent fall for no reason, or just not be able to get out of bed that day. dreamMakerS provides just such a place for children of parents with MS where they can express the feelings that they may otherwise have kept hidden, ask the questions they may never have felt comfortable asking, and enjoy a community they might never have found. In less than a year, we have assembled an incredibly talented, dedicated and passionate team of volunteers, board members and expert advisors and are pioneering programming to create the special place I've described.

Connecting, supporting, and empowering children of parents with multiple sclerosis is what dreamMakerS does. The mission is accomplished through a variety of programs that incorporate social, educational and support components. Some of the upcoming programs families have to look forward to include improvisation classes, a family fun day, and cooking classes! We are extremely excited to offer a Big-Brother, Big-Sister Program, which will pair adult children of parents with MS with children with common interests. Each program dreamMakerS offers also provides a support component, facilitated and supervised by an experienced social worker. All dreamMakerS' programs and services are free to families living with MS. In founding dreamMakerS, I was inspired by the song Moon River - which my dad sang to me at bedtime on the nights he was able to make it up the flight of stairs - "Oh, dream maker, you heart breaker, wherever you're going, I'm going your way..." To learn more about dreamMakerS and our mission to Connect, Support, and Empower Children of Parents with Multiple Sclerosis: please visit our website: www.msdreammakers.org or email Liza Levenson at Liza@msdreammakers.org.

Louis Rittberger Cleveland, OH



Louis and his Mom

Louis Rittberger's is producing his second annual fundraising event, "Imagine", in Cleveland, Ohio to help raise funds for the Nancy Davis Foundation for MS

Center Without Walls program. Last year the event raised \$60K for MS research and we congratulate him on his mission to raise even more funds this October 2011.

His mother was diagnosed with MS 20 years ago and since that time he has made it his quest to find a cure. He produced his first fundraising event "Imagine" in Mayfield Heights, Ohio on September 11, 2010 and we are honored to have been chosen as the beneficiary!

This year the event will take place on October 1st at the State Theatre, Playhouse Square in Cleveland. The evening will be packed with fabulous eats from many of Cleveland's finest food establishments, amazing live entertainment, silent auction and some dramatic surprises! For more information visit our website at www.erasems.org/2011-imagine-gala/

Thank you to Louis for your incredible dedication and enthusiasm to help us get one step closer to winning our Race to Erase MS!





Nancy Davis Foundation for Multiple Sclerosis 1801 Avenue of the Stars, Suite 1400 Los Angeles, CA 90067

Address correction requested

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SAVE THE DATE

19th Race to Erase MS Gala Friday, May 18, 2012

Hyatt Regency Century Plaza

For more information please call 310-440-4842 or visit www.erasems.org

2012 MS Roundtable Saturday, May 19th 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.

2011 Major Sponsors "Rock and Royalty to Erase MS"

Thank you for your generous support!











