



***"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. Together as a team we know we can cross that finish line and win our Race to Erase MS!"***

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## 19th Annual *Glam Rock to Erase MS*



Stevie Wonder

On Friday, May 18th, we celebrated our 19th Annual Race to Erase MS. Once again the Race hosted a variety of musical performances throughout the evening including Fitz and the Tantrums, *American Idol*'s David Cook who entertained the crowd, the incredible vocals of The Tenors and the showstopping legendary Stevie Wonder who had everyone on their feet dancing with many outstanding ovations. The night was kicked off with an exciting celebrity fashion show featuring Authentic Icon inspired by *American Idol* and Andrew Charles, the hip rock 'n roll fashion line by Andy Hilfiger.

Honorees at this years gala included MS survivor and legendary actress, Teri Garr, and philanthropists, Deb and Bill MacMillan, who were honored for their outstanding contributions to funding vitally important multiple sclerosis research. Hosts for the evening were Marg Helgenberger, Cybill Shepherd, Jason Kennedy and Taylor Hicks. The evening also included a live auction hosted by Shaun Robinson and Jason Kennedy with incredible vacations to Vomo Island Fiji and Hilton Bora Bora Nui. Items such as a private yacht trip and a St. Regis European get-away were big sellers for the evening.

In Race to Erase MS tradition, the night ended with a stellar and unforgettable performance of "Lean On Me" led by Stevie Wonder with Fitz and the Tantrums, David Cook and Taylor Hicks, among many others joining the stage. Guests couldn't leave without picking up the coveted gift bag donated by Tiger J and designed by Dee Hilfiger filled with over 50 unbelievable items. Sweet E's Bakeshop spoiled guests with scrumptious cake pops to top off the evening.

We would like to thank our amazing presenting sponsors 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 breathtaking orange floral arrangements were generously donated by Mark's Garden. Mindy Weiss, well known event designer, created an auction atmosphere that was truly Glam Rock. Thank you to Voli Vodka, Pineridge and FIJI Water, for their incredible support. 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 3, 2013 for our 20th Anniversary Race to Erase MS at the Hyatt Regency Century Plaza!



"Lean on Me" Finale



@RacetoEraseMS



Search: Nancy Davis Foundation

## Contact Us

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## Message from Nancy Davis President and Founder



*With our 20th Anniversary upon us, now more than ever we are determined to find a cure and put a stop to this debilitating disease. It is incredible to think just a short 20 years ago there were no drugs on the market to stop the progression of MS and now there are 8 therapies available with many more in the pipeline to help relieve symptoms and in some cases halt or reverse the disease. Each and every one of you who has contributed to this cause should be very proud of the ground breaking accomplishments to bring hope to millions of people. I want to also take a moment to remember a great man who served many years on our Scientific Advisory Board, Dr. George Eisenbarth. He was a brilliant scientist who I know will be missed by many and his passing is a tremendous loss to the scientific community. We thank him for his incredible service to our Board.*

*We are committed to our mission to fund research grants to Young Investigators (YI) as we strive to support the most highly advanced 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.*

*Make sure to keep your eye out for upcoming items featured in our "Orange You Happy to Erase MS" month of May Campaign! We are thrilled at how our awareness campaign has grown over the last five years and we thank our partners, celebrity supporters and media who helped us raise important funds for MS research. We are truly indebted to those who support the campaign by purchasing product and we want you to know that every t-shirt sold is one more ray of hope for a cure. Make sure to visit our website and click on SHOP!*

*With our 20th Anniversary around the corner on May 3, 2013, we have big plans for the most spectacular evening celebrating the many accomplishments that have been made to put an end to MS. We are so elated to honor Sharon Osbourne and Jack Osbourne at this years event. They are true role models to everyone living with this disease and to anyone caring for a loved one with MS. Best wishes to everyone for the holidays and see you at our Race to Erase MS!*

## Center Without Walls Semi-Annual Symposium with our Team!

We just completed our semi annual Winter Symposium led by our prestigious Scientific Advisory Board Dr. Henry McFarland, Dr. Luanne Metz and Dr. Daniel Reich who truly are the most stellar team of scientists. We are so grateful to have the commitment, vision and insight of these great minds ensuring we only fund the best and the brightest to lead us to a cure.



Dr. Henry  
McFarland



Dr. Luanne  
Metz



Dr. Daniel  
Reich



Dr. Emmanuelle  
Waubant

Dr. Emmanuelle Waubant is our Director of our Center Without Walls program and manages the communication of our centers on a daily basis. In addition to the regular use of high-technology communication tools, the research doctors of our program come together to share scientific accomplishments through monthly telephone conference calls, standard scientific advisory meetings and MS symposiums. 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 and winning our Race to Erase MS!

## Over 35 Million Raised in the last 19 Years...

### Help us make our 20th Anniversary Count!

The Race to Erase MS was founded in 1993 and we began our quest to find a cure for multiple sclerosis raising over 35 million in the last 19 years. Since 1999 specifically, our Race to Erase MS has raised \$25,075,507 in contributions and we have funded MS research grants and programs totaling \$19,615,995 through our Center Without Walls program.

Our core focus is to assist in the treatment and ultimate cure of MS. 71% of all foundation spending since 1999 has been on program activities, funding cutting edge research through our Center Without Walls, which is greater than the 65% recommended by the Better Business Bureau Wise Giving Alliance.

We are proud of the tremendous strides that have been accomplished in our Race to Erase MS and the advances that have been made towards finding a cure. We thank everyone who has supported our vision and to all those who "race" with us in unwavering generosity in our journey to find a cure for MS. The landscape of MS... There are now 8 drugs with FDA approval to help stop the progression of MS and 3 more coming out in the very near future. The future is bright for the person being diagnosed today with multiple sclerosis.

## Announcing Honorees for the 2013 Race to Erase MS! Sharon Osbourne and Jack Osbourne



We are so honored to recognize Sharon Osbourne and Jack Osbourne at our 20th Anniversary Race to Erase MS event on May 3, 2013. Sharon has been instrumental in the support of the Race to Erase MS over many years and she has become a national role model in the fight to find a cure for MS. After her son Jack was diagnosed with multiple sclerosis early this year, she has made a tremendous impact in the community in a short amount of time

by educating the public, raising awareness, and funding vitally important multiple sclerosis research. Jack is a man of great courage and truly a champion in the eyes of so many that live with this disease. His brave step to speak out about his diagnosis brought multiple sclerosis to the attention of the world, bringing hope to so many millions that suffer with this autoimmune disease.

We look forward to honoring these two 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](http://www.erasems.org) for more information on the event and full biographies on our honorees.

We look forward to celebrating with everyone in May 2013 so make sure to mark your calendars! For more information call 310-440-4842.



# SAVE THE DATE!

FRIDAY, MAY 3, 2013

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](http://www.erasems.org)

### RACE TO ERASE MS

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**Leslie Weiner, M.D.**  
University of Southern California

**CWW Medical Director**  
**Emmanuelle Waubant, M.D.,**  
University of California, San Francisco



# Annual MS Forum and Expo

May 19, 2012

Hosted by WebMD, the most spectacular panel of MS research scientists from the Nancy Davis Center Without Walls Program informed guests on their recent advances in MS therapies outlining the progression of their MS research that will lead us to a cure. Dr. Rohit Bakshi from the Brigham and Women's Hospital at Harvard discussed quantitative neuroimaging, studying atrophy of grey matter in the brain, and identifying MS at early stages using advanced MRI techniques. Dr. Dennis Bourdette of OHSU updated the audience on the progress being made to protect nerve fibers from degeneration and the regeneration of myelin. Furthermore, Dr. Calebresi at Johns Hopkins also expanded on the progress of creating anti-inflammatory and neuroprotective therapies like enhancing remyelination to improve cognitive function. Dr. Emmanuelle Waubant of UCSF talked about the presentation of MS in pediatrics and how to treat them, while the other MS research investigators discussed other advances in the genetic mechanisms of MS, molecular entities roles in MS, and how the immune system plays a role in the nervous system and MS. Our guest panelists included Demetrius Omphroy, Janice Dean, Dean William Singleton, David Osmond, Clay Walker, Claudia Curry Hill, and Teri Garr who shared their personal experiences with MS lending advice and inspiring hope and courage to those battling the disease.

Guests enjoyed resources and interactive activities available to them through our health and wellness expo prior to the forum. We thank all our wonderful Expo partners for their valuable participation. Companies such as EMD Serono, TEVA Neuroscience, and Questcor passed out information on different MS therapies and treatments. Other companies like PMTD Flexiciser, Karman Healthcare, and Avacore Technologies showcased advanced technologies and equipment to aid those with physical and mobility disabilities due to MS. Other vendors catered to the emotional and mental aspects of MS: Melissa Tufeld, PhD, gave advice and guidance on managing the psychological hurdles of MS and coping with the disease, while Moving from the Inside provided information on the benefits of somatic movement to help manage MS symptoms. We also would like to extend a warm thank you to the Hyatt Regency Century Plaza, Fiji Water, Sweet E's, Zico, Clementine's, Zenify, and Harry and David for their invaluable donations to this very important educational opportunity.

This annual event is free and open to the public and we welcome you, your family, and friends to attend this unique event to ask questions, receive resources and information, and to speak directly to top MS research doctors 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. Next year's event will take place on Saturday, May 4th, 2013 at the Hyatt Regency Century Plaza so make sure to save the date and spread the word about this amazing and inspirational event!



Teri Garr and  
Nancy Davis

David Osmond and  
Dr. Dennis Bourdette



Dr. Leslie Weiner

Claudia Curry Hill and  
Katie Brass



David Osmond, Demetrius Omphroy, Clay Walker, Dr. Peter Calebresi, Dr. Emmanuelle Waubant, Nancy Davis, Janice Dean, Dr. Dennis Bourdette, Lynn Palmer, Dr. Leslie Weiner, Dr. Murugaiyan Gopal, Claudia Curry Hill, Dean Singleton, Dr. Kevin O'Connor, Dr. Robert Bashki, Dr. Lilyana Amezcua



Clay Walker, Nancy Davis  
and Demetrius Omphroy

Forum Participants



MS Expo Partners and Participants



Nancy Davis speaking to Participants

## Pediatric MS

By Dr. Emmanuelle Waubant, UCSF

In up to 10 percent of MS cases, the disease starts under the age of 18, and is thus named pediatric MS. In young patients, such a diagnosis implicates doctors, social workers, neuropsychologists, parents and teachers in supporting the affected child to optimize chances of developing a normal life as a young adult. It used to be thought that if you were under 20 years of age, you did not have MS. Now children as young as two have been diagnosed.

The Regional Pediatric MS Center at UCSF is a Center of Excellence that was initiated in 2006 with a 6-year to provide multidisciplinary clinical services to families affected by this disease. Since then, Dr. Waubant, the Director of this clinic, and her team have seen over 250 pediatric patients affected by MS or mimics thereof. These children are evaluated by the neurologist to confirm or rule out the diagnosis, as well as by the neuropsychologist who makes recommendations to optimize school environment. The social worker spends time with parents and children to troubleshoot emotional, behavioral and health insurance issues to insure the best global care.

Thanks to this multidisciplinary approach to pediatric MS, Dr. Waubant and her team have unraveled key features of pediatric MS such as distinct characteristics of the disease on the MRI and spinal fluid of patients younger than 11, when the disease looks different and challenges doctors. Until their ground breaking work, these atypical characteristics at disease onset resulted in delayed diagnosis and care, and thus, higher chance of disability. The team has described that patients under 11 have a brain MRI showing larger and more poorly defined MS scars compared to adults with MS, and also that MS scars in young patients often go away within a few months, which very rarely occurs in adults. Understanding the mechanisms underlying these MRI features may help develop new treatments for adult MS. The team has also described that the spinal fluid of young patients with MS can show more inflammation than in adults (i.e. the number of white blood cells is much higher than in typical adult MS) and is often missing hallmark features of MS spinal fluid (i.e. oligoclonal bands and elevated IgG index). Finally, they have shown that younger patients with their first MS event can have a problem thinking and be lethargic, which is common with adult MS. Now that these distinct features in younger patients have been identified, and that widespread education is delivered to care providers about these, accurate diagnosis in children with MS is made earlier, i.e. at the time early treatment can better prevent disability onset.

The team has developed strong links with many pediatricians, neurologists and child neurologists all over the West Coast with an emphasis on state-of-the-art care, education for care providers, teachers and families, and creative research to advance prevention, diagnosis and treatment in children with MS and ultimately adults. Dr. Waubant is also the editor of the first book on pediatric MS that has disseminated worldwide the recent knowledge accumulated by top teams.

(PEDIATRIC continued on Page 13)

## Steps Toward a Cure

By Wendy Gilmore, PhD, USC

All of us who are affected by MS—patients, families, friends, health care providers, physicians and scientists engaged in MS research, and so many more—want to cure this complex and troublesome disease. When we think about a cure, we often imagine a sudden breakthrough that can be applied immediately to all patients with MS. In reality, a cure is more likely to emerge slowly from a solid base of knowledge that is constantly expanding as new discoveries are made—mostly from years of careful, detailed, step-by-step research, but also, from sudden or surprising insights as we integrate new information with the old. So what steps are needed to bring a cure forward? The following is a summary of 4 steps that are essential to the development of a cure for MS, and are topics of intense research efforts in MS at this time.

(1) Early detection. One of the mysteries about MS is that we really don't know when it starts—we just know when symptoms are disturbing enough for a patient to seek help from a medical professional. Although the onset of symptoms can occur at any age, MS is most commonly diagnosed in young adulthood, and is increasingly recognized in children. This suggests that the abnormal processes in the central nervous system (brain, spinal cord and/or optic nerves) that lead to MS begin early in life. If early signs of MS can be identified at any age, interventions could be applied to keep MS from establishing itself as a chronic disease. Early detection involves knowledge in many areas of MS research, including skills and tools that are needed to diagnose MS, an understanding of the contribution of genetic and environmental factors to MS in all stages and forms, and natural differences in disease characteristics in children compared with adults (young, middle and older age groups), in individuals of different races or ethnicities, and between girls and boys and women and men. As this knowledge expands, we may also be able to predict individuals who are at risk of developing MS, before symptoms begin, and institute monitoring for early detection.

(2) Control of inflammation. Inflammation clearly plays a role in MS—it is not only readily detectable in magnetic resonance imaging (MRI) scans, but the majority of FDA approved treatments for MS are anti-inflammatory medications that minimize relapse frequency and delay disease progression. Inflammation is central to the damage that occurs in the brain, spinal cord or optic nerves in MS, and may also interfere with attempts to repair the damage. However, inflammation, and specific types of immunity, can also play beneficial roles, “cleaning” up the damage and setting up conditions that are conducive to healing, or repair of the damage. We can think of “bad” inflammation as a storm that causes damage to a house, and “good” inflammation as the crew of workers that clean up the damage in preparation for repairs. Thus, in order to develop more precise and effective tools to control inflammation, it is important to know when and

(CURE continued from Page 11)



# photo gallery: 19th Annual Race to Erase MS



Bill Jr., Deb, Cammy, Kiki  
and Bill MacMillan



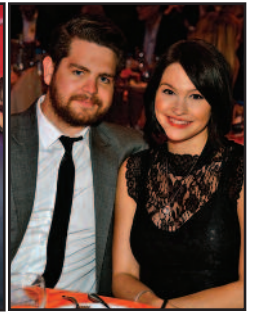
Lea Thompson with  
her Daughters



Kendall and Kylie Jenner  
with Andy Hilfiger



Nancy Davis, LaToya Jackson,  
Stevie Wonder



Jack and Lisa Osbourne



Nancy Davis, Jim MacMillan,  
Deb and Bill MacMillan



Lean on Me Finale with Stevie Wonder



Nancy Davis, Teri Garr,  
and Molly O'Neill



Julie and Dwight  
Opperman



Cybill Shepherd and  
Nancy Davis



Stephanie Perkins and Guests



Ken and Brooke Lande,  
Debbie and Jimmy Lustig



Marg Helgenberger,  
Barbara Davis, Nancy Davis



Lynn Palmer and  
Jon Lovitz



Laura and David McKenzie,  
Nancy Davis and Elizabeth Stanton



Kim Richards,  
Kathy and Rick Hilton



Valerie and David  
Osmond



Nancy Davis and  
Bonnie Pfiefer



Jerry and Tawny  
Sanders



Ken Rickel, David Osmond, Nancy Davis, LaToya Jackson,  
Kim Marshall, Lynn Palmer, Nicola and Chris Odgers



Lamar Odom and  
Khloe Kardashian Odom



Christine Devine with  
Fitz and the Tantrums



David Cook

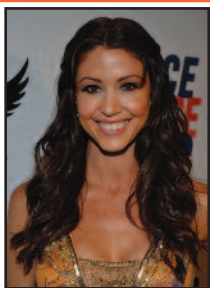


Mary Connor and Guests



DeeDee and Jack Klunder,  
Dean Singleton





Shannon Elizabeth



Andy Hilfiger, LaToya Jackson, Nancy Davis



Marivi Garcia, Sherry Corday, Debbie Eaton, Kathy Fisher, Robin Correll, Julie Finnerty, Rose Fahey, Silvia Baker and Tracy Danza



Taylor Hicks and Pia Toscano



Cindy Hutchings and John Maze, Jennifer and Bret Keltner



Brandon Davis and Nancy Davis



Andy Hilfiger, Paul and Lynn Palmer, Victor Micallef, Clifton Murray, Nancy Davis



Debbie Patillo, Donna Estacio, Trisha Taylor



Mariella and Isabella Rickel



Evevlyn and Bob Rickel



Jessica and Clay Walker



Kim MacMillan, Cybill Shepherd, Nancy Davis, Kiki, Deb, Bill, Cammy MacMillan



Nancy Davis, Alexander and Lindsay Davis



Richard David and Mark Held



Erika Tucker-Weinberg and Nancy Davis



Carmel and Ryan Giese



Shainaz Donnelly, Mark Burg and Family



Carry Nolan and Claudia Curry Hill



Dana Davis, Nancy Davis and Robert Anthony



Jason Davis and Nancy Davis



Nancy Davis and Shaun Robinson



Robert Shapiro and Nancy Davis



Jan Miller and Guest



Frank Cintamani and Nancy Davis



Cyrus Wilcox and Clementine Ford



Janice Dean and Guest



## ms health tips and resources

### Balance Wear

BalanceWear® is a new balance correcting vest that has the potential to restore a patient's balance and mobility immediately upon application, in many cases permitting a return to independence, accelerated rehabilitation and healing, and the ability to again have the productive and independent lifestyle that was lost due to imbalance. BalanceWear, the result of a decade of research is now available to patients through a network of specially trained physical therapists in our patented BBTW® (Balance Based Torso Weighting) method. Clinical improvements are seen in approximately 80% of people immediately upon application. Demonstrated independent clinical research has shown same day improvements in walking and mobility in people with multiple sclerosis and Parkinson's disease. This non-invasive technology is effective without the use of pharmaceuticals or surgical procedures and for those patients who respond, the results are immediate upon application. To see same day balance correction videos, published peer reviewed clinical research and much more, please visit [www.motiontherapeutics.com](http://www.motiontherapeutics.com).

### Yoga and MS

Yoga has proven to be well suited for those with MS and can be adapted to an individual's ability. It involves a series of poses that are held to increase both strength, flexibility and balance.

Yoga can also improve energy level and mood, which is wonderful for one of the most difficult and hidden symptoms of MS, fatigue. Yoga improves muscle tone, balance, coordination, and it can help reduce muscle spasms. A specific program called MyMS Yoga is an exercise program created to manage MS symptoms and stay active. It has been featured on ABC News and consists of modified Yoga poses catering to those with mobility and balance issues. For more info visit: <http://www.msactivesource.com/ms-yoga>

### Brain Games for MS

Multiple sclerosis resources like WedMD and MultipleSclerosis.com offer a free suite of online brain games filled with cognitive challenges for the MS community. These online brain games are designed for people with MS to stimulate and improve cognitive function. The games provide a series of fun and interactive cognitive challenges and puzzles. Many of the games challenge the player's processing speed, memory, attention and task switching ability. Check out these sites for Brain games and cognitive stimulation exercises.

[www.multiplesclerosis.com/Brain Games](http://www.multiplesclerosis.com/Brain Games)  
[www.webmd.com/MS Gaming Center](http://www.webmd.com/MS Gaming Center) and Puzzles

[www.cognifit.com/more brain games and cognitive stimulation exercises](http://www.cognifit.com/more brain games and cognitive stimulation exercises)

### Coolture for MS

Van DiBernardo, a former DKNY designer, conceived Coolture in 2009. Van suffers from heat intolerance due to Multiple Sclerosis. But it's only recently that Coolture has been able to move into production, thanks to Dr. Thomas P. Stewart.

Cooling core body temperature improves physical endurance for the chronically ill, but also improves endurance in athletes. In 2008, Nike introduced a pre-cool vest to the swimmers in the Beijing Olympics because it was determined that cooling core body temperature could improve physical endurance by 21%. That vest was never made available for purchase. And while there are other cooling products in the marketplace, their medical and/or industrial appearance are not desirable for street wear. Coolture is marketing its unique product to those with chronic illness, specifically Multiple Sclerosis; but also to recreational golfers and athletes who wish to remain active during hot weather. For more information about the product and story, visit [www.coolture.net](http://www.coolture.net).

### Swimming is a Good Activity for MS

Water exercise is one of the best workouts for people with Multiple Sclerosis – water makes the body buoyant and keeps our core temperature cooled. Using aquatics, people with MS can work-out longer and harder, while in a safe environment; cushioned from the risk of injury.

There's an innovative MS aquatics program on the University of Dayton (UD) campus, Dayton, Ohio, that combines water exercise for people with MS and practical experience for students in the Health Sciences. The weekly program is free to anyone with MS and their support partner or companions.

The UD program is designed so each person can work out in the water at their own level, and the participants' ability levels vary widely from fully-ambulatory to being dependent on wheelchairs. The ability to swim is not a requirement, and the workout can be done in waist deep water.

A whole lot of socializing goes on within this active group, as well, which can be as important as the physical act of exercise. It is entirely too easy to become reclusive and isolated when living with any chronic disease and it is therapeutic to share experiences with others who also have MS.

We welcome any inquiries as to how this program could be duplicated on other college campuses!

By Laura Kolaczowski - Swimming Program Director; Kurt Jackson PT, PhD, GCS



## ms in the news

### BG-12 Oral Drug for MS

A new oral medication to treat patients in the early stages of multiple sclerosis has shown considerable promise in two clinical trials.

The medication is on track to become just the third oral drug available to M.S. patients, and potentially the safest and most effective, experts said. The second oral drug, called Aubagio, was approved just last week.

The two new studies, published online in The New England Journal of Medicine, found that the drug BG-12, developed by Biogen Idec, reduced relapse rates in patients with relapsing M.S. by about 50 percent. The drug also significantly reduced the frequency of new brain lesions often associated with these attacks, and slowed the progression of disease compared with a placebo.

The studies were Phase 3 trials, a last step on the road to drug approval. The Food and Drug Administration is required to make a decision about the drug's approval before the end of this year.

Article excerpt from:  
[http://www.nytimes.com/2012/09/20/health/research/bg-12-pill-shows-promise-in-suppressing-multiple-sclerosis-relapses.html?\\_r=0](http://www.nytimes.com/2012/09/20/health/research/bg-12-pill-shows-promise-in-suppressing-multiple-sclerosis-relapses.html?_r=0)

By Laurie Tarkan  
Published: September 19, 2012

### MS Discovery at OSHU

Portland -- Oregon Health & Sciences University researchers are celebrating their new discovery they say stands a good chance of helping people suffering from multiple sclerosis and a range of other neurological disorders.

They've discovered high levels of a particular enzyme not usually found in the brain, only in those with brain damage

due to MS, stroke and other conditions.

Lead researcher Larry Sherman Ph.D. believes if they can figure out how to block the enzyme, the brain can repair itself, where insulating shields around nerve cells have been damaged or destroyed. The next step is to find a drug or combination of medicines that block the enzyme. Researchers will first try to find a successful treatment using Japanese Macaque monkeys at the Oregon National Primate Research Center, affiliated with OHSU.

The small percentage of the monkeys have a disease similar to MS in humans. "These animals get this disease spontaneously and if we can reverse this disease process in these animals--show that it's safe--it does its job. We are hopeful we can then take this to patients, hopefully in the next 10 to 15 years if not sooner," said Sherman.

Article excerpt from  
<http://www.kgw.com/lifestyle/health/MS-Breakthrough-176907071.html>  
By Tim Gordon

### Aubagio Daily Tablet Approved

Aubagio (teriflunomide), a once-daily tablet for adults with relapsing forms of MS (multiple sclerosis), has been approved by the US Food and Drug Administration (FDA).

Novartis' Gilenya and Tysabri from Elan Corp are said to be more effective than teriflunomide. Director of the Division of Neurology Products in the FDA's Center for Drug Evaluation and Research, Russell Katz, M.D., director of the Division of Neurology Products in the FDA's Center for Drug Evaluation and Research, said:

"In a clinical trial, the relapse rate for patients using Aubagio was about 30 percent lower than the rate for those taking a

placebo. Multiple sclerosis can impair movement, sensation, and thinking, so it is important to have a variety of treatment options available to patients."

According to clinical trial results, the following side effects among people taking Aubagio were reported: hair loss, nausea, abnormal liver test results, and diarrhea.

Aubagio has been approved for the initial phases of the disease. Doctors should carry out blood tests beforehand to make sure liver function is normal. During treatment with Aubagio, liver functions tests should be performed periodically. Aubagio is manufactured and marketed by Sanofi Aventis.

Article excerpt from <http://www.medicalnewstoday.com/articles/250293.php>  
By Christian Nordqvist

### Intravenous immunoglobulin (IVIG)

Intravenous immunoglobulin (IVIG) is a medicine often used to boost the body's immune system and make it better able to fight disease. It is made from donated blood fluids. Treatment with IVIG may improve function and lengthen the time before a relapse in people who have relapsing-remitting MS. It does not seem to help slow the progression of MS. IVIG can also lengthen the time before a second attack in people who take it after the first attack.

But IVIG is extremely expensive, not widely available, and not considered practical for long-term treatment of MS. It sometimes may be used to treat a severe relapse if you either cannot take or do not respond to corticosteroids.

Article excerpt from:  
<http://www.webmd.com/multiple-sclerosis/tc/multiple-sclerosis-intravenous-immunoglobulin-ivig-topic-overview>

## 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 2012-2013 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:

**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: The focus of our research is to try

to understand the role the immune system has on the body's brain stem cells ability to repair. In the earlier stages of MS the body is able to repair some of the damage in the central nervous system by recruiting the body's own source of brain stem cells, namely neural stem cells and oligodendrocyte progenitor cells, to the sites of injury. 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, we have demonstrated that activation of the CXCR1 receptor in these cells modulates some of their basic biological responses, such as migration (perhaps towards injured tissue) and their ability to differentiate to a functional cell. It is our aim to expand upon these findings and with the support from the Race to Erase MS we will be able to further define the role of inflammation in NSC and OPC repair, thereby improving our knowledge of MS and opening new doors for future treatment strategies designed to target repair of the central nervous system.

**Lilyana Amezcua, MD**  
**USC Keck School of Medicine**



Exploring the influence of ancestry in MS characteristics: Most current MS knowledge derives from studying MS in caucasian individuals. While MS affects multiple

backgrounds, the genetic and ethnic contributions in MS are less understood. Hispanics, a European derived population, represent an admixed population, defined as a population with recent ancestry from two or more continents- the other being Asian and in some proportions, African. These characteristics are observed in our findings where Hispanic/Latino Americans have a mixture of European and Asian traits in the way their MS behaves. Hispanic diversity in both ancestry and clinical manifestation brings advantages to studying MS.

By analyzing genes that are common to the human genome (GWAS), in particular ancestral genes that are differently distributed across populations we may be able to identify how genes influence clinical and radiological manifestation of MS and treatment response that are common to all affected by MS. This approach may be able to identify high-risk subgroups which may be at risk of progression and could benefit from earlier, aggressive treatments. This includes identification of opti-cospinal forms of MS more common to Asians.

**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 T helper 9 (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.

### 1st Year YI Grant Recipients:

**Dimitrios Davalos, Ph.D.**  
Gladstone Institutes, University of California, San Francisco



Imaging methodologies and the activation of microglia: MS damages the myelin that surrounds and protects axons, the fibers that neuronal cells use to

communicate with each other and with all muscles and organs. Without their protective myelin sheath, axons fail to conduct neuronal signals properly, and eventually, this causes the symptoms of MS. Some of the damage to myelin is done by immune cells known as microglia. These resident immune cells of the brain normally survey and protect the brain from insults. However, microglia are among the earliest cells to show signs of activation in the MS brain. Importantly, signs of early microglial activation are detectable before the onset of demyelination or the destruction of axons, an indication that they may have a key role in initiating the pathological events that lead to MS.

We recently developed cutting-edge imaging methodologies to study the sequence of events that link the activation of microglia to the formation of MS-type lesions. To do so, we use a combination of powerful microscopy and genetic technologies that allow us to follow the behavior of individual fluorescently-labeled cells inside the living brain or spinal cord, in real time. Our current studies are aimed at detailing the damaging interactions between microglia and axons and understanding the mechanisms that regulate

them. Our ultimate goal is to discover targets for therapeutic intervention, by identifying the cellular events and the specific pathogenic signals that lead to loss of neuronal function in MS.

**Margarita Dominguez-Villar Ph.D.**  
Associate Research Scientist in Neurology Yale School of Medicine



Molecular signature of Th1-Tregs:

MS is a chronic inflammatory disease of the central nervous system with infiltration of activated inflammatory cells into the CNS that damage both myelin and axons. It is associated with a general loss of immune regulation as commonly seen in human autoimmune diseases. Some years ago a loss of regulatory T cell function in patients with relapsing/remitting (RR) MS was reported by the Hafler lab, although the molecular mechanisms responsible for this dysregulation are still poorly understood. Our recent data show that regulatory T cells from RRMS patients have an increased ex vivo frequency of Th1-type, IFN $\gamma$ -secreting T-bet+Foxp3+ Tregs compared to healthy controls. Our data indicate that Treg reprogramming to a newly described Th1-type of IFN $\gamma$ +Foxp3+ Tregs may play an important role in the pathogenesis of MS. The goals suggested in this proposal focus on analyzing how Foxp3 binding targets are modified in Th1-Tregs due to the presence of T-bet and how these modifications are reflected in the global gene expression pattern of the cells and the defect on suppression observed in patients with MS.

The support of the Race to Erase MS will help us to describe the molecular signature of Th1-Tregs as well as the ex vivo requirements for their generation. Moreover, it will help to design new therapeutic strategies for the treatment of MS.

### (CURE continued from Page 5)

how inflammation is causing damage, and when and how it is setting things up for repair during MS.

(3) Protection against further damage. It has become evident that damage to myelin, the protective, insulating sheath that surrounds nerves (similar to the insulation on electrical cords), can expose nerves and nerve cells themselves to additional damage by “bad” inflammation. Damaged nerves and nerve cells have difficulty maintaining the energy that is required to function efficiently, and are at risk to stop working altogether. Protecting exposed nerves (a process that is called “neuroprotection”) from additional damage could buy time until repair can be arranged. Some of the currently approved and future treatments for MS may act as indirect neuroprotective agents by discouraging “bad” inflammation and promoting “good” inflammation.

(4) Promotion of repair. One of the many insights that have emerged from MS research is that repair of central nervous system injury in MS happens even as the damage occurs, indicating that repair within the MS brain is possible. It is believed that as MS persists or progresses, repair processes that are normally carried out by stem cells become blocked. Since repair is essential to the development of a cure, identification of the blocks and the design of treatments to remove these blocks are areas of active and intense investigation at this time. Knowledge from these studies will be supplemented with an understanding of the conditions required for normal stem cell functions during development and disease.

To individuals dealing with MS on a daily basis, progress in MS research is undoubtedly much too slow. But remarkable gains have been made, especially in the last ten years, in each of the four steps.

## highlights from the lab, new grant recipients continued

**Pilot Study Summaries 2012-2013:**  
Support for a focused research project that is novel and will unravel new aspects of MS.

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



Can gene tests be used to predict the severity of disease course in MS and better understand disease progression? In this study

doctors from Johns Hopkins are collaborating with doctors from Harvard to determine if there are genes that determine why some people have mild MS and other people have more severe forms of MS.

The Hopkins doctors are using a new tool called OCT that provides a microscopic picture of the nerves in the back of the eye called the retina. OCT can measure exactly how much nerve damage has occurred in this one part of the brain that can be seen from outside the body, and it turns out that these measurements of how healthy the nerves are in the eye provide information about the health of the brain in general. Thus “the eye may be a window into the brain”. This information about brain health will be combined with genetic information obtained from the same patients in blood samples sent to the Harvard group.

By combining the two pieces of information researches may then determine if mutations in specific genes are associated with mild or severe type of MS. Most of the MS genes identified to date are related to the risk of getting MS and point towards the immune system. This study is designed to allow the doctors to discover if there are genes related to the nervous system that may determine the type or severity of a person's MS. It could also lead to new targets in order to develop therapies for progressive MS.

**Howard L. Weiner, M.D.**  
Robert L. Kroc Professor of Neurology  
Brigham and Women's Hospital



Role of Microglia in MS: Microglial cells are one of the four major types of cells in the brain. They serve many important functions including reacting to infection, cleaning up damaged tissue, and

maintaining brain homeostasis. Microglial cells can either be protective or damaging depending on their state. Very little is known about microglial cells in MS. We have developed new ways to characterize microglial cells based on gene profiles and unique surface markers. This will allow us to study microglial cells both in the EAE animal model of MS and brain tissue from MS patients. We believe that microglial cells may have a protective effect in MS and enhancing this protective effect will allow the nervous system to heal better and prevent progressive forms of the disease.

With support from the Race to Erase MS, we will begin for the first time to characterize microglial cells during the course of brain inflammation in both animals and patients. As part of these studies, we hope to identify structures on the surface of microglial cells that can provide new targets for the development of a unique class of drugs for the treatment of MS. We postulate that if we are able to modulate microglial cells so they have protective function, this could have a major impact on the disease. It is also possible that targeting microglial cells can be done in conjunction with other approved MS therapies thus enhancing their effects.

**William D. Rooney, Ph.D.**  
Advanced Imaging Research Center  
Oregon Health & Science University



Assessment of Mitochondrial Function in MS Gray Matter:

Multiple sclerosis has traditionally been viewed as a white matter disease of the brain

and spinal cord. Although focal white matter lesions are the pathological hallmark of the disease, significant gray matter involvement, including accelerated gray matter loss, now is recognized as an important and early disease feature.

Mitochondria serve as the tiny power plants for producing cellular energy and are vital for maintaining cell health and integrity. Impairment of cellular energetics could put cells at risk for degradation. Cells store energy in chemical form and many of these chemicals can be measured using a non-invasive magnetic resonance technique called “phosphorus spectroscopy.”

In this project, we will use phosphorus spectroscopy to investigate gray matter energy status in MS. This work is important in that it may provide an approach to identify individuals with increased risk for gray matter loss early in the disease before significant disability has accrued. Early detection would allow assessment of therapeutic interventions that may improve brain energy status and rescue tissue at risk for loss. Through support from the Race to Erase MS we will refine these measurements and make them more practical for general use.

### Multiple Sclerosis Symptoms:

#### Most common early symptoms of MS include:

**Loss of balance, Weakness in one or more limbs, Blurred or double vision.**

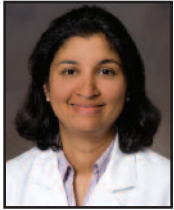
#### Less common symptoms of MS may include:

**Slurred speech, Sudden onset of paralysis, Lack of coordination, Cognitive difficulties.**



## highlights from the lab

**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:

We are actively recruiting subjects with Acute Optic Neuritis (AON) for this 24-week, randomized, placebo-controlled, pilot trial to study the effects of oral lipoic acid on nerve fibers in the affected eye of AON subjects. Subjects are randomized to receive either lipoic acid 1200 mg or placebo once a day for 6 weeks. Primary outcome measure is optic atrophy as measured by OCT at three and six months after the baseline visit.

We have encountered challenges in subject recruitment for the study due to our original inclusion criteria, hence made changes in these criteria in a stepwise fashion since summer of 2011. In Sept 2011, our Institutional Review Board (IRB) approved the extension of the subject inclusion into the study to up to 14 days of AON diagnosis. Since Feb 2012, we are approved to include AON subjects who have been treated with corticosteroid prior to study drug initiation. In June 12, 2012, we got IRB approval to include AON subjects who have pre-existing MS diagnosis. Since Feb 2011, we screened more than 17 subjects for the study but enrolled 4 (key reasons for failure to include were: use of steroids, duration > 8 days, previous diagnosis of MS). With the changes now made in the inclusion criteria, we believe recruitment should improve.

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 and possibly for MS relapses.

We are grateful to Race to Erase MS for its generous support in making this innovative research possible.

### Center Without Walls Update:

**Research that has been previous funded and is still ongoing through our program:** The Center Without Walls was very active in the past year, accomplishing many research projects thanks to the support of the Race to Erase MS.

During this past year, the Foundation has supported six very promising junior scientists to help them establish their state-of-the-art research. Dr. O'Connor at Yale is focused on advancing the understanding of the role of special immune cells, called B cells, and their products, and how they regulate the immune response in the brain of patients with MS. Dr. Kellan at University of Southern California is studying the cells that provide insulation (myelin) to nerve cells and how to stimulate stem cells so they become myelin forming cells that will help MS scar repair. Dr. Amezcua at University of Southern California is studying what are risk factors for MS in Hispanics, and the specific presentation of the disease in this ethnic group as this may unravel new information on MS in general. Dr. von Buedingen at University of California San Francisco is developing techniques to encourage human stem cells to become nerve cells and tries to understand how cells that produce antibodies can affect those nerve cells. Dr. Ratchford at Johns Hopkins is defining how to monitor the status of nerve cells in the optic nerve in order to study drugs with a potential for neuroprotection. Dr. Gopal at Harvard is deciphering the role of small proteins, called interleukins, in MS progression in novel animal models.

Several pilot grants were also awarded to highly exciting and innovative research projects. Dr. Yadav at Oregon Health and Science University is performing a clinical trial of a new promising drug, oral lipoic acid, in MS patients with inflammation of the optic nerve, with the hope this may limit injury occurring during MS relapses. Dr. Calabresi at Johns Hopkins is examining the protective and reparative effects of a small molecule, GC-1, in animal models of MS. Dr. Waubant at University of California San Francisco is analyzing whether the bugs found in the gut of pediatric patients with MS are different from healthy children, as bugs may be important for the development of a normal immune

response. Dr. Gilmore at University of Southern California is advancing our understanding of brain cell repair using a new drug called ICG-001 in animal models of MS.

All these talented scientists and doctors share the results of their research at Center Without Walls program meetings which foster the blossoming of promising junior researchers in order to one day cure MS.

### **(PEDIATRIC continued from Page 5)**

The group at UCSF has also developed several research projects. Dr. Waubant is currently running a large research study in the US aimed at unraveling the triggers of pediatric MS, and hopefully adult MS as well. In this study, 640 pediatric MS cases and 1,280 pediatric healthy children will be studied in terms of their environmental exposures (i.e. vitamin D, Epstein Barr virus, cytomegalovirus, herpes simplex virus, diet, etc) and their genetic make-up. In addition, the effect of specific factors in the environment together with specific genes will be studied as some may enhance the effect of others, which then could result in much increase in the risk of MS in a given individual with all these risk factors. As of today, 150 individuals (with pediatric MS or healthy) have provided blood for the study and their parents have answered a very comprehensive questionnaire on what happened during pregnancy and shortly after birth that may be important triggers for MS. Fourteen centers all over the US are participating to this effort.

We expect that this study will provide key information on factors that trigger MS, not only in children but also in adults. This study is leveraging the fact that it is easier to study risk factors closer to the time of exposure (i.e. in children) and would be very challenging to do in adult MS as most of the information regarding exposure to various environmental factors by the time adult patients are first evaluated has been forgotten.

With the end of the National MS Society grant for clinical activities and education, and the difficult economy, Dr. Waubant is concerned that it will soon become more difficult to serve families affected by pediatric MS and educate care providers, thus resulting in impaired care for these children. She remains hopeful that new sources of funding will continue fuel the research on and care of pediatric MS patients so they can live the healthiest possible life.

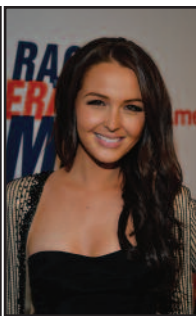


## photo gallery, continued

## Race to Erase MS



Molly O'Neill and Teri Garr

Andrea Ficzynski (center)  
with Guests

Camilla Luddington

Barry Hirschfeld, Noa Hirschfeld,  
Nancy Davis, Arlene HirschfeldGuests with Ken Rickel  
and Mary Connor

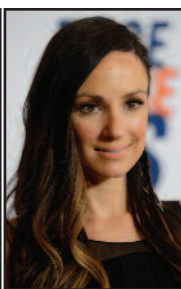
Lauren and Michael King



Noel and Dina Cohen

Kathy Hilton, Nancy Davis,  
Barbara Davis, Lynn PalmerNancy Davis, Carol Mizel,  
Cindy and Steve FarberNancy Davis and  
Lyndi Hirsch

Dr. Emmanuelle Waubant and Guests



Catt Sadler

Anna Theiler, Bob Theiler, Donna MacMillan,  
Ariana Chase, Kiki MacMillan, Drew Anderson

Stevie Wonder

Mayra Veronica (center)  
with GuestsBecky Hennrich  
with Guest

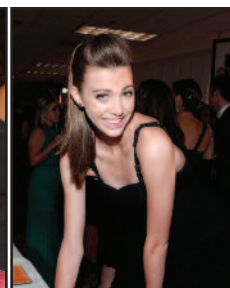
The Tenors

Nancy Davis and  
Stephanie PerkinsKendall and  
Kylie JennerNancy Davis and  
Tony WilliamsSteven Cojocaru  
and Steve FarberHyatt Regency Century  
Plaza Desert

Maddie Hasson

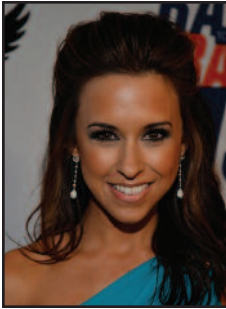
Francesca Eastwood  
and Nancy DavisCamille Grammer and  
Taylor Armstrong

Marleah Leslie and Guest



Kalia Prescott

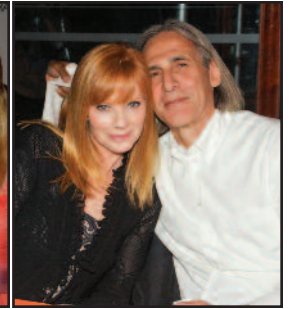




Lacey Chabert

Jacob Lusk, Taylor Hicks and Pia Toscano  
with Nancy Davis and Family

Fashion Show

Carmen Electra  
and Nancy DavisMarg Helgenberger and  
Alan FinkelsteinPaul Rosenberg and Guest, Jordan Cohen,  
Robert Rickel, Megan Levant

Dove and Jeff Rudman and Guests



Josie Loren



Pam Levine and Guest



Lean on Me Finale

Maureen and Gary Tucker,  
Erica and Adi WeinbergJordan and John Davis  
and Nancy DavisJosie Loren and  
Cassie Scerbo

Pia Toscano

Linda Thompson, Tracy Danza  
and Kathryn BeltonCammy MacMillan and  
Nancy Davis

Guests with AJ Brass



Megyn Price

Chelsie Hightower and  
Anna Trebunskaya

Joyce and Stanley Black and Guest

Ace Young and  
Diana DeGarmo

David Cook and Band

Lonnie Paul, Kirsten Sarkisian,  
Lynn Palmer, Dr. Liliyana AmezcuaJason Kennedy and  
Shaun Robinson

Rob Knepper and Guest



## Tissue Damage and MS

**By Kevin C. O'Connor, PhD**  
**Yale School of Medicine**

Dr. Kevin O'Connor is a recent grant receipt of our Center Without Walls Young Investigator initiative. The following is an updated summary of the on-going work on his lab: Much of the tissue damage that occurs in the MS brain and spinal cord is led by the immune system.

Among the cells participating in this assault are B cells. These 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 antibodies that then bind antigens marking them for immune mediated destruction. When this occurs to self-antigens, rather than foreign antigens, B cell autoimmunity is at work. This process may be occurring in MS central nervous system (CNS) lesions, but many of the details remain unknown.

Dr. Kevin O'Connor's group at Yale School of Medicine recently determined that the MS CNS harbors a related network of B cells and secreted antibodies. They have put forth an effort to identify the antigen(s) that these B cells recognize and several candidate antigens have been identified. In their current work they are evaluating if these newly identified antibody-antigen pairs can be found in the cerebrospinal fluid and blood of MS patients. If they are, they will correlate their presence with clinical parameters in an effort to identify new biomarkers for MS.

He and his team are equally focused on understanding the role these antibodies play in the destruction of tissue in the MS CNS. Recently, they 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 funds provided by the Race to Erase MS have been vital in allowing novel and innovative approaches to understanding how the immune system contributes to MS. These studies have contributed to a further understanding of how immune cells affect tissue damage and perpetuate the MS disease process. This work stands among the fundamental steps required for development of new therapeutic approaches for treating MS.

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ERASE  
MS**

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**Erase MS**

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NOW**

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NEW PRODUCT IN 2013!**

**Join our Virtual Race to Erase MS!  
Raise much needed funds for MS research and  
help us Erase MS  
from anywhere in the world!**

**Raise \$2,000 or more for MS research and you can earn tickets to attend our star-studded 20th Anniversary Race to Erase MS Gala in Los Angeles on May 3, 2013!**

**Visit <http://virtualrace.kintera.org/erasems>  
to sign up today!**

**Together as a team we will cross the finish line  
and WIN our Race to Erase MS!**

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## inspiring words from our supporters

## Deciding to Have a Baby Even if I Have MS

By Nicole Whitmore



I was diagnosed with MS in 2004 when I was 24 years old. But MS has not stopped me. I got married in 2005 to the greatest partner I could ever ask for and I have been involved with the Race to Erase MS for the last several years. I look forward to the Race to Erase MS annual gala and MS Forum and Expo every year.

When I began my journey to fulfill my dream of having a family, I didn't think much of it. It was something I was determined to do despite my MS. My friends at NDF asked me if I would speak to other young women who were contemplating pregnancy and were fearful because of their disease. I was flattered that my decision to become a parent living with multiple sclerosis was considered courageous.

I never really thought of it as "courageous," becoming a mother was just something I had always planned on no matter what. When you are a little girl and dream about your future as a mommy, it doesn't include MS, but in my reality it did, but this was not going to stop me from fulfilling my dream. I made the decision to have a baby based on the fact that there are many people living with MS who have had children and never had a relapse during or after delivery. Also, my doctor told me if you do have a relapse post-pregnancy, it doesn't usually leave you any more disabled than you were before becoming pregnant.

Although it had never even crossed my mind that having a baby with MS would be a problem, I still thought of all the

"what ifs". However, I decided to think positively and try anyway. My road to pregnancy, like many others, was not easy, but in the end I was finally pregnant and healthy. I had an amazing pregnancy and we welcomed our beautiful baby girl on October 24, 2011. I felt better than ever and what they say about MS and pregnancy is true! My symptoms were less severe and I had no relapses during or after my pregnancy. I did have some MS issues before I became pregnant. I have minor optic neuritis affecting the center of my vision in both eyes making it hard to read small print. It also makes it hard for me to focus on things while moving, like street signs while driving. My vision got much better while pregnant and I enjoyed the "positive symptoms" of pregnancy. A year after my pregnancy my vision is back to "normal" and by "normal" I mean my MS normal - not perfect.

My last MS issue is my legs, which get tired and heavy. I can go to the grocery store, go to work, walk around my office if I need to, but I wouldn't probably go for a walk, or choose to walk around the mall for a couple of hours. When my legs get tired it tends to make my eyes worse...it is like physical tiredness affects all of my symptoms. I feel like such a complainer writing all of this stuff down. I really don't feel like I have all of these issues, but listing them sounds awful. Regardless, none of these symptoms prevent me from being a loving supportive mother to my baby.

I LOVED being pregnant and felt GREAT! I still feel good, post-delivery and always try not to worry about any issues after delivery. When I went into labor, I had the option of getting the epidural and I did! It made things a lot less painful and less stressful, and I think that is important for everyone, especially those of us with MS! There is always the fear that things could go wrong, but I just try to think positive and live by the saying, "everything happens for a reason." As I

mentioned, I had a lot of trouble getting pregnant and I thought maybe I shouldn't have a baby because of my MS, but when I got pregnant, I knew it was right. I knew it was meant to be, and I love my baby girl, and I am very happy she is here. I wouldn't change any of it. I always wanted to have kids and I didn't want to give up that dream because of this stupid disease, I already have to give up other stuff.

Furthermore, I understand there is the fear of not being able to care for a baby. It makes it that much more important for us to stay healthy. If you have a strong support system and keep positive thoughts you will be fine. We can only hope for the very best. Lastly, finding the right doctor is also important. I love my doctor and she really helps me make decisions that are smart and good for me and my family. She is very supportive and I appreciate that because it makes dealing with MS so much easier!

Making this decision is tough, but you need to do what is best for you, and what you want for your life and your family. There are no guarantees...and it is scary to think of the worst, so I try not to! As many of you know, living with MS can be challenging, and some days you want to give up. My beautiful baby girl, Abigail, gives me another reason to stay positive, and she ALWAYS makes me smile! Just one look at her and my heart fills with love and happiness! It is an amazing feeling – one I am glad I didn't pass up just because I have MS. This is just one of the ways that I, Colie, Stand Up Against MS!



## inspiring words from our supporters

# Pardon Me Doc, But I have What?

By Jill Jelley



In the week before Christmas 2010 the left side of my face and mouth went numb, then my left arm. I thought I was having a stroke as I knew the warning signs. My husband took me to the emergency room where they performed a cat scan and then we waited and waited. I began to feel foolish and thought, any minute now they are going to throw me out of here and tell me they need the bed for real patients. Then the doctor came back with the opposite news, “we saw a lot of abnormalities on your brain so we are admitting you. You will have an MRI in the morning and the neurologist will see you after that.” When I saw the neurologist the next day the first thing he said was “We think it’s MS.” What? Where did that come from? It was so surreal. Here was something so far out of left field I was for once at a loss trying to grasp what the doctor was telling me. I was kept in hospital for a week as they ran a barrage of every test I think ever invented. “All the tests came back normal but we still can’t be sure, let’s do another MRI in 3 months.” Quick to latch on to what seemed like good news I asked “so MS is off the table?” “No I still think it’s MS.”

Fast forward 6 months, and new insurance means a new doctor. The wonderful neurologist I see is a specialist with stroke patients. We discuss my symptoms and I return for the results of the MRI. “You have an enhancing lesion. I think it’s MS.” Again with this diagnosis? I am not convinced and as she refers me to an MS spe-

cialist neurologist we wager a steak dinner on the outcome. Well as of February 2012 guess who owes her former Neurologist a steak dinner? I spent some time going through all sorts of emotions: Denial, anger, sadness, more anger, more sadness. Strangely enough, a feeling of dogged determination then swept over me..

Now I tried to find out everything I could about the disease. I felt frustrated as I searched the internet. So much information but there seemed to be no definitive place to go. Different sites had different colors and dates for MS awareness, different research and information. Then I wondered how do we in the community not know more about this disease. As a former nursing student and with multiple generational nurses in my family, who also ‘knew the disease’ but didn’t ‘really know’ what it meant, it was maddening to me.

By chance my husband and I found the Nancy Davis Foundation online and were so impressed with the Center Without Walls program. Finally! Here were doctors, researchers and specialists from all over talking to each other about MS. Not rushing to be published, not looking for individual credit and accolades. We knew we wanted to do something to help. I joined the Virtual Race to Erase MS and thanks to the travel I had done when I was younger, I saw donations pour in from London, Australia, Boston, Los Angeles and Orange County. A friend even was traveling through the Dominican Republic at the time and managed to send a donation. It is amazing how people react to news such as this. I was so fortunate to have so many friends and acquaintances support me. Some didn’t and I guess that’s a learning curve too. I was fortunate to make my goal of \$2000 and my husband and I were excited to be able to attend both the Race to Erase MS Gala and MS Forum and Expo this past May.

I think the one thing I have taken away with this disease is that if I have to have it I want to raise more awareness about it. I want to scream and shout “Hey everybody, this disease has been here a long time and we still don’t have a cure yet.” It’s as if this disease sits in a dark closet and no one wants to talk about it. No wonder no one knows much about it outside of those with it, their family and their friends or those actually working with it. It is such a personal choice for people to disclose that they have it. Careers can be affected by the sentence “I have MS”.

It is also such a different disease for everybody affected, as is the course the actual disease takes and so it is difficult for people to grasp as we “look fine” so much of the time. For a lot of us it is considered “manageable,” but for so many it is not. It is also not an “economical” disease to have and so many forgo treatment due to high costs. Nor is it a pretty disease as they have yet to design hipster mobility aides or incontinence pads (although that new cooling vest is pretty “cool” I must admit!)

My husband and I really hope that in some small way we can keep chipping away at increasing awareness and at the same time raise more money to help the Nancy Davis Foundation for MS win their Race to Erase MS!


**RACE  
TO  
ERASE  
MS**



## Alex and Ani join us in our Race to Erase MS and a Daughter Honors her Mother in the Process

We are thrilled and so honored to have Alex and Ani as a year round partner in our Race to Erase MS. We were introduced to them through another great supporter, Deana Cimorelli, and we owe her much thanks for her hard work to support the cause. Learn more about Deana's journey with MS in her story below. Alex and Ani have been phenomenal at building awareness and educating the public about multiple sclerosis through a very special cupcake charm they designed just for us! It is a symbol and reminder of how sweet life can be and they have already raised over \$40,000 for MS research! At the heart of Alex and Ani is the most powerful of all positive energies, love. Their passion for making the dreams of charitable organizations come true is channeled through Charity by Design, a unique department focused solely upon giving. Charity by Design empowers charitable organizations to reach their goals by sharing what they do best, the power of positive energy through innovative, creative design. Their customized symbolic charms capture the essence of a charity making it more accessible to the public while raising awareness and funds. Proceeds are donated directly to non-profit organizations who strive to enhance the quality of lives.



 Alex and Ani  
(+) ENERGY

**Deana Cimorelli, has been a partner in our month of May campaign for the last three years and this cause is near and dear to her heart. Below is her story in her words:**

My mother got diagnosed with multiple sclerosis when I was six months old. By the time I was five, she was paralyzed from the neck down. Growing up with a parent who has an illness is challenging in itself, let alone one that has zero mobility. Due to my mother getting sick so early into my life, she was unable to have any other children which left both me and my father as the primary care-givers. Life was not easy growing up, I missed out on a lot but now that I am an adult and see the value of what I learned so early on in my life, I would not change it for anything. I would however give anything to have my mother back for one day to see what I have done in her honor, to show her the business that I built and to have her meet her two beautiful grandchildren. Life is now very bitter sweet for me but through my campaigning with the Race to Erase MS I feel that part of her is still here with me and I now am able to help others living with MS.



Nicki Castonguay and Deana Cimorelli

I own a bakery, The Bakery Boutique, in Smithfield, RI. and one day I had the usual wedding consultation booked for an evening appointment and in walks Nicki. Through our "getting to know you" stage I found out that she was the VP of Charity by Design for Alex and Ani. Well we got to talking and within the next month I felt like we were in a whirlwind frenzy having lots of lunches, coffee runs and even holiday parties! I had asked her if they currently had a bracelet where the proceeds go back to MS and she told me they didn't....the wheels started to spin and before I knew it, five months later, the Race to Erase MS cupcake bangle was born. The Charity by Design team at Alex and Ani were so gracious in working closely with me as we designed the perfect cupcake for Race to Erase MS! We hosted an exclusive pre-sale event at my bakery prior to the official launch date of the bangle. I saw that as a huge opportunity to sell the bracelet and to start generating donations for MS research. I was so excited and wanted to invite the world! I had a lot of great sponsors who also contributed to the evening to make it even more memorable. I was also very happy to hear that at the end of the night, they actually ran out of the cupcake bangle and that had never happened before at an event. I was so pleased and knew that my mother would have been so proud of me to know that I did all of this along with the help of some great people!



Since the official launch of the bangle, I am happy to say that I have been an instrumental part in the funds that have been raised for the Race to Erase MS. It brings me such pleasure to know that I am helping others with my efforts. I am currently orchestrating a MS Moonlight Walk that will take place in May 2013 throughout the Orange Campaign. I was very excited and honored to be part of the 19th Annual Glam Rock event along with my husband and two lovely gals from Alex and Ani. I will continue to do what I can to help raise awareness to this disease and look forward to next year's gala!



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### TRIBUTE CARD PROGRAM

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

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

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

## SAVE THE DATE

**20th Race to Erase MS Gala  
"Love to Erase MS"  
Friday, May 3, 2013**

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

**2013 MS Roundtable  
Saturday, May 4th  
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.

## 2012 Major Sponsors "Glam Rock to Erase MS"

Thank you for your generous support!



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