

RACE TO ERASE MS

Contents Winter 2013

Imaging Consortium Funded by
Race to Erase MS / p. 3

MS Forum and Expo / p. 4

Salt in Your Diet and MS / p. 5

Steps Toward a Cure / p. 5

Photo Gallery: Erase MS Gala /
p. 6-7, p. 14-15

Health Tips & Resources / p. 8

Mood 24/7: Are you depressed?
make sure to monitor / p. 9

Center Without Walls Program
Update / p. 10

Your Diet and MS / p. 16

Cognitive Function / p. 17

Social Security Disability / p. 18



@RacetoEraseMS



Search: Race to Erase MS

Contact Us

Race to Erase MS
1875 Century Park East,
Suite 980
Los Angeles, CA 90067

Phone: 310.440.4842
Fax: 310.471.4975
www.erasems.org

20th Anniversary "Love to Erase MS"

On Friday, May 3, 2013, we celebrated our 20th Anniversary Race to Erase MS. Honorees at this year's gala included Sharon Osbourne and Jack Osbourne, who were honored for their many contributions to heightening the profile and educating the public about MS and for doing everything possible to help raise funds for research. Hosts for the evening were Neil Patrick Harris, Terrence Jenkins and Marg Helgenberger. The evening also included a live auction called by Howie Mandel and Shaun Robinson, during which lucky bidders walked away with items including a five-night stay at unique St. Regis hotels, Vomo Private Island Resort in Fiji, a week charter of a gorgeous yacht to the Bahamas, and the new Aston Martin Centenary Edition DB9 auctioned in celebration of the iconic British sports car's 100-year history.

The Race to Erase MS had the most memorable and exciting line up of performers headlined by Grammy Award-winning artist and musical icon Elton John. His captivating performance was a once in a lifetime opportunity for everyone there as he played solo at his piano and sang a full hour of his amazing hits including "Tiny Dancer," "Your Song," "I Guess That's Why They Call It the Blues," "Rocket Man," and "I'm Still Standing." Taio Cruz who was joined by DJ Havana Brown to perform hits "Break Your Heart," "Higher," and "Dynamite." In Race to Erase MS tradition, a rendition of "Lean On Me," directed by Greg Phillinganes, was performed as the finale of the evening led by Aly & AJ Michalka who were joined on stage by Nancy Davis, Cybill Shepherd, Marg Helgenberger, Kelly Osbourne, LaToya Jackson, David Faustino, Kim Richards, and more.

Guests could not stop talking about the spectacular floral arrangements of orange roses in a heart shape generously donated by Mark's Garden. Everyone commented on their extraordinary beauty. Mindy Weiss, well known event designer, created a festive auction atmosphere. Guests couldn't leave without picking up the enormous Race to Erase MS gift bag so generously donated by Tiger J, enjoying such items from Laura Geller, Marware, Rolling Razor, M Day Spa, to name a few. 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, Hyatt Regency Century Plaza, Aston Martin 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. Thank you to Beam Global, Neo Water and Nice Guy Limo for their incredible support. Thank you to Cristophe Salon and MAC, who created the amazing hair and makeup for our celebrity presenters.



Lisa and Jack Osbourne, Nancy Davis,
Kelly Osbourne and Sharon Osbourne



Elton John



Taio Cruz

Please make sure to save the date May 2, 2014 for our 21st Race to Erase MS at the Hyatt Regency Century Plaza! Details to follow or check our website www.erasems.org.

Message from Nancy Davis

President and Founder



It gives me so much hope that we are on the fast track to finding a cure with the ninth therapy now approved for MS and many more medications in the pipeline to help relieve symptoms and in some cases halt or reverse the disease.

Thank you to the brilliant research scientists who continue to forge ahead with ground breaking concepts, bringing hope to millions of people living with this disease.

We are so honored to have Dr. Henry McFarland, Sharon Osbourne and Jack Osbourne join our Board of Directors this year. 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, NIH in shaping the future direction of clinical research at NIH. Sharon and Jack Osbourne are true role models to anyone caring for a loved one with MS and anyone living with this disease. Jack, even though he has MS did the impossible and competed in the very rigorous "Dancing With the Stars" and made the finale. What an awe inspiring role model to all those that suffer with MS.

May 2, 2014 marks our 21st birthday celebration and we are in the midst of planning the most spectacular Race to Erase MS gala at the Hyatt Regency Century Plaza. We are so elated to recognize Dean Singleton at this years event with our "Medal of Hope" award for his inspiration and dedication to this cause. He is a role model of positivity to everyone living with this disease. Thank you to all of our generous supporters who year after year help to make this event the most memorable evening in Los Angeles. We look forward to a successful 2014.

We are also excited at how our "Orange You Happy to Erase MS" campaign has grown and we thank our partners, celebrity supporters and media who helped us raise important funds for MS research. We have many partners who support us year round so know that you can always look for gifts or special items for yourself and support MS research at the same time. Alex and Ani is one of our amazing partners www.alexandani.com and Chiquita Tropicals just joined our cause and their product is available directly from our shop or on Amazon!

Peace and Love.

Our Race to Erase MS Honoree! Dean Singleton to Receive 2014 "Medal of Hope"

We are so honored to recognize Dean Singleton at our 21st Race to Erase MS event on May 2, 2014. Dean has been instrumental in the support of the Race to Erase MS over many years and he has made a huge impact in the fight to find a cure for MS. Dean was diagnosed with multiple sclerosis in 1986 and has never let his MS dictate his life. He lives every day to the fullest and truly a champion in the eyes of so many that live with this disease. He has never stopped with supporting efforts to educating the public, raising awareness, and funding vitally important multiple sclerosis research, bringing hope to so many millions that suffer with this autoimmune disease. Below is his a brief biography on this great man we are so honored to recognize at our May 2, 2014 Race to Erase MS Gala:



Dean Singleton and Nancy Davis

William Dean Singleton, 62, is Chairman of the Board of MediaNews Group, publisher of 57 daily newspapers and over 100 non-daily publications in twelve states. He founded the company in 1983 and in its 30th year, MediaNews is the Nation's second largest newspaper company as measured by circulation and the largest privately held newspaper concern. Singleton is also Chairman and Publisher of The Denver Post, the company's largest newspaper; and Chairman and Publisher of The Salt Lake Tribune. He began his newspaper career at the age of 15 as a part-time reporter in his hometown of Graham, Texas, and bought his first newspaper at age 21. He served on the board of the Newspaper Association of America from 1993 until 2004, and was Chairman of NAA in 2002 and 2003. He was Chairman of the Associated Press Board of Directors from 2007 until 2012. In addition, he is on the boards of the Rocky Mountain Multiple Sclerosis Center, the National Sports Center for the Disabled, The Helen G. Bonfils Foundation, The Denver Center for the Performing Arts and the Winter Park Recreational Association.

We look forward to honoring this generous individual who has been a tremendous inspiration and 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.

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

New Consortium Using Advanced Imaging Approaches for Research

Magnetic resonance imaging (MRI) is a powerful tool used to study disease activity in multiple sclerosis (MS) and plays a central role as a key outcome measure in clinical trials of promising new therapies. It is the only real tool to measure the progression of MS. Standard imaging approaches measure inflammatory activity in the form of gadolinium enhancing lesions and new T2 lesions. After years of study, it is clear that these measures capture only a small portion of MS disease related changes taking place in the brain and spinal cord. Newer, more advanced imaging approaches provide a more complete picture and are better correlated with clinical disability. In addition, some of these advanced techniques hold promise as readouts for trials of novel therapies that promote remyelination or neuroprotection.

So why aren't these new techniques a routine part of clinical trials? The answer is that these trials involve many sites with different scanning equipment and expertise. Implementing advanced imaging approaches requires sharing of expertise and careful calibration of the scanning protocols, all of which is time consuming and costly. Instead, most studies go for the lowest common denominator, that is, the scans are done at the lowest level that can be achieved across sites. This pragmatic approach is one reason why newer imaging approaches remain in the exploratory phase despite evidence that they could be powerful outcome measures.

To address this gap, the North American Imaging in Multiple Sclerosis Cooperative (NAIMS) was established in 2012 with the support of the Race to Erase MS. The inaugural meeting took place on May 17, 2012 at the foundation's Center Without Walls semi-annual Symposium in Los Angeles. Current NAIMS core members include: Rohit Bakshi (Harvard), Peter Calabresi (Johns Hopkins), Ciprian Crainiceanu (Johns Hopkins), Beth Fisher (Cleveland Clinic), Roland Henry (UCSF), Jiwon Oh (Johns Hopkins/University of Toronto), Daniel Pelletier (Yale), Daniel Reich (National Institute of Neurological Disorders and Stroke), Bill Rooney (Oregon Health Sciences), Nancy Siccotte (Cedars-Sinai), and Jack Simon (Oregon Health Sciences).

The over-arching goals of the NAIMS group are to: (1) develop reliable imaging-based measures for disease-progression in multiple sclerosis (MS); (2) accelerate the pace of MS research in North America by creating standardized imaging protocols for use in clinical research; (3) and bring together a range of imaging expertise focusing on the study of MS. At the conclusion of the inaugural meeting in 2012, an application to obtain funds for the NAIMS pilot project was submitted to the Race to Erase MS. The second NAIMS meeting took place on May 2, 2013 at the Center Without Walls Symposium.

In July 2013, the Race to Erase MS awarded funds to the NAIMS Cooperative for the first NAIMS pilot project. In addition, the American College of Radiology Imaging Network (ACRIN) has agreed to provide a central repository for data storage and analysis at a reasonable cost. Currently, work on the project includes setting up a central website to collect imaging protocols from each site, with the goal of creating a standardized imaging protocol to be tested later this Fall. By pooling expertise, each site can benefit from the knowledge of the others, and unlike previous studies, these scanning sessions will aim for the most advanced imaging approaches possible. The organization and goals of the project fit perfectly with the Foundation's mission to promote the sharing of resources and knowledge to accelerate progress in MS research. With the support of the Race to Erase MS, the NAIMS Cooperative is raising the bar for MS imaging research in North America. Article provided by Dr. Nancy Siccotte, Cedars-Sinai.

RACE TO ERASE MS

BOARD OF DIRECTORS

Nancy Davis, Chairman
Barbara Davis
Dana Davis
Steve Farber, Esq.
Teri Garr
Claudia Curry Hill
Avril Lavigne
Debbie and Jimmy Lustig
Dr. Henry McFarland
Sharon Osbourne
Jack Osbourne
David Osmond
Lynn Palmer
Ken Rickel
Tawny Sanders

THE CENTER WITHOUT WALLS SCIENTIFIC ADVISORY BOARD

Luanne M. Metz, MD, FRCPC
Calgary MS Clinic Director
Professor, Department of Clinical
Neurosciences

Henry McFarland, M.D.
Scientific Director
Cumming Foundation

Daniel S. Reich, M.D., Ph.D.,
Investigator,
Translational Neuroradiology Unit,
Johns Hopkins

CENTER WITHOUT WALLS PROGRAM RESEARCH CENTERS

Dennis N. Bourdette, M.D.
Oregon Health Sciences University

Peter A. Calabresi, M.D.
John Griffin, M.D.
Johns Hopkins Hospital

David Hafler, M.D.
Yale University School of Medicine

Nancy Siccotte, M.D.
Cedars-Sinai

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

Howard Weiner, M.D.
Brigham & Women's Hospital, Harvard

Leslie Weiner, M.D.
University of Southern California

MS Forum and Expo

Our 2013 Spring event was a huge success!

Hosted by WebMD, the most spectacular panel of MS research scientists from the Race to Erase MS Center Without Walls Program informed guests on their recent advances in MS therapies.

Dr. Adam Kaplin from Johns Hopkins discussed the relationship between depression and MS. Since the immune system attacks the brain and spinal cord, it causes the nervous system to release hormones and neurotransmitters that cause changes in body function and behavior. Dr. Kaplin discussed ways to treat depression. Dr. Emmanuelle Waubant from UCSF and Dr. Peter Calabresi from Johns Hopkins updated the audience on the progress being made to treat progressive MS. Lastly, many of the MS doctors on the panel discussed new therapies in the pipeline for MS, and highlighted the newest MS drugs, BG 12, which has proven to be effective to treat MS. Other MS research investigators discussed advances in the genetic mechanisms of MS, new technologies for imaging and reading MRIs, how MS affects cognition, the importance of diet and vitamins and how the immune system plays a role in the nervous system and MS. Jack Osbourne also joined the panel as a guest and shared his personal experience with MS lending advice and inspiring hope 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 of our wonderful Expo partners for their valuable participation. Companies such as EMD Serono, TEVA Neuroscience, Genzyme, and Questcor passed out information on different MS therapies and treatments.

Other companies like Academy Medical Equipment and Nova showcased advanced medical equipment to aid those with physical and mobility disabilities due to MS. Brad's Raw Foods, Nekter Juice, and MILA displayed samples of their health products and demonstrated the benefits these foods provide those with MS. Yogaworks and Kara Wily Pilates advocated for exercise and how it can benefit those with MS to enhance flexibility, decrease spasticity, and reduce stress and pain. Casa Colina, People's Care, and the Department of Disability shared with guests the services and programs they provide to the community to help those with MS. We also would like to extend a warm thank you to the Hyatt Regency Century Plaza, Sweet E's, POM, Clementine's, and Groundworks Coffee 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. A special thank you for the generous support of Associated Television International for making the forum accessible to those who can not attend. Make sure to visit WebMD.com or our website to view the podcast of this special forum.

Our Race to Erase MS Winter MS Forum took place on December 8th at the Hyatt Regency Century Plaza and was a huge success. Our 2014 Spring MS Forum and Expo will take place on Saturday, May 3rd also at the Hyatt Regency Century Plaza. Make sure to save the date and spread the word about this amazing and inspirational event! For more information please visit www.erasems.org or follow us on facebook or twitter for up to date information. You are welcome to call our office at 310-440-4842.



The Lockes, Nancy Davis and The Whitmores



Forum Panel

Jeanette Elsner, Dr. Waubant, Claudia Curry Hill



(Back row) Dr. Adam Kaplin, Lynn Palmer, Dr. Daniel Pelletier, Dr. Howard Weiner, Dr. Robert Bashki, Dr. Peter Calabresi, Dr. Leslie Weiner
(Front row) Dana Davis, Claudia Curry Hill, Jack Osbourne, Sharon Osbourne, Nancy Davis, Dr. Emmanuelle Waubant, Dr. Vijayshree Yadav



Sharon Osbourne talking with guests

Dana Davis and Lynn Palmer



Jack and Sharon Osbourne and Nancy Davis with the Ziff Family and Friends

Salt in your diet can have an impact on your MS

Study by Dr. David A. Hafler, M.D.

For the past few decades, health officials have been reporting increases in the incidence of autoimmune diseases such as multiple sclerosis. Now researchers at Yale Medical School, Harvard Medical School and the Broad Institute have identified a prime suspect in the mystery – dietary salt.

In the March 6th issue of the journal *Nature*, Yale researchers showed that salt can induce and worsen pathogenic immune system responses in mice and that the response is regulated by genes already implicated in a variety of autoimmune diseases.

In accompanying papers in the same issue of *Nature*, researchers from Brigham and Women's Hospital and Harvard identified the key molecular pathway involved in the response to salt and the Broad Institute sketched out the regulatory network of genes that governs this autoimmune response.

“These are not diseases of bad genes alone or diseases caused by the environment, but diseases of a bad interaction between genes and the environment,” said David Hafler, Gilbert H. Glaser Professor of Neurology and professor of immunobiology Chair of Department of Neurology, and senior author of the Yale paper.

The research grew out in part by an observation that eating at fast food restaurants tended to trigger an increase in production of inflammatory cells, which are mobilized by the immune system to respond to injury or pathogens but in autoimmune diseases attack healthy tissue. Researchers at Yale and colleagues in Germany led by Dominik Mueller wanted to know whether high salt content in diet might induce the destructive immune system response that is the hallmark of autoimmunity.

They found that adding salt to the diet of mice induced production of a type of T cells previously associated with autoimmune diseases and that mice on salt diets developed a more severe form of an MS animal model, experimental autoimmune encephalomyelitis. The research at the Broad, Brigham and Women's Hospital, Harvard University and Yale University expands the understanding of how one type of immune cell – known as a T helper 17 or Th17 cell – develops, and how its growth influences the development of other kinds of cells involved in the immune system. Reconstruction of this molecular circuitry confirmed the surprising role of salt.

“The question we wanted to pursue was: how does this highly pathogenic, pro-inflammatory T cell develop?” said Vijay Kuchroo, a senior scientist at Brigham and Women's Hospital and a Broad associate member. Kuchroo is also the Wasserstrom professor of neurology at Harvard Medical School and co-director of the Center for Infection and Immunity at Biomedical Research Institutes. “Once we have a more nuanced understanding of the development of the pathogenic Th17 cells, we may be able to pursue ways to regulate them or their function.”

“Humans were genetically selected for conditions in sub-Saharan Africa, where there was no salt,” Hafler said. “Today, Western diets all have high salt content and that has led to increase in hypertension and perhaps autoimmune disease as well.” Hafler noted that all test tube cell biology is performed based on the salt levels found in blood and not in the tissues where immune cell ultimately travel to fight infections. That may have been a reason salt's role in autoimmunity has gone undetected.

“We may have been using the wrong concentrations of salt in our experiments for the past half-century,” Hafler said. “Nature did not want immune cells to become turned on in the pipeline, so perhaps blood salt levels are inhibitory.”

Patient trials to assess affects of salt on autoimmune diseases are underway. “The value in doing an unbiased analysis is that we're able to understand a lot more about the molecular biology at play and put forth a completely novel process,” said Aviv Regev, a Broad Institute core member and an associate professor of biology at MIT. Regev is also an Early Career Scientist at Howard Hughes Medical Institute and the director of the Klarman Cell Observatory at the Broad.

Hafler is not waiting with his own patients. “I already recommend that my patients use a low-salt, low-fat diet,” he said Markus Kleinewietfeld was lead author of the Yale-led study.

photo gallery: 20th Annual *Race to Erase MS*



Jack, Sharon and Kelly Osbourne

Ken Rickel, Nancy Davis,
Mariella and Isabella Rickel

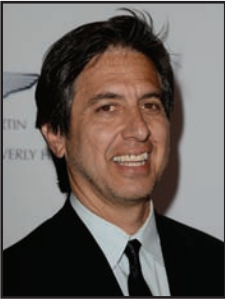
Elton John and Sharon Osbourne



Penny and Rod Stewart



Tommy and Dee Hilfiger



Ray Romano

Brenda Richie, Camille Grammer, Kathy Hilton,
LaToya Jackson, Nancy Davis, Kim Richards, Ken Rickel

Elton John



Paul and Lynn Palmer

James Tupper,
Nancy Davis, Anne Heche

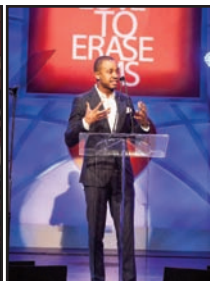
David and Laura McKenzie

David Burtka, Neil Patrick Harris
and Sharon OsbourneShaun Robinson, Howie Mandel,
Vanessa ThanosNancy Davis
and Barbara DavisArlene Hirschfeld, Debbie Lustig,
Carol MizelSherry Corday
and Debbie EatonMark Held, Mary Jane Partlow, Cheryl
Cecchetto, Richard David

Bill and Debbie MacMillan

Clementine Ford and
Cybill Shepherd

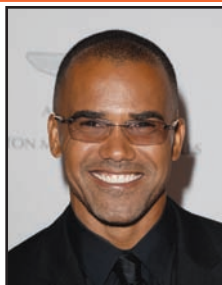
Tawny and Jerry Sanders

Deb Macguire, Cammy MacMillan,
Steve Ponce, Jimmy LustigGuests with Dean Singleton, William
Singleton, Claudia Curry Hill, Kelley Hill

Terrence Jenkins

Victoria Paige and
Nancy Davis

Gloria Allred and Julie Opperman



Shemar Moore

Marcy Taub, John Coleman,
Cynthia OttSilvia Baker, Marivi Garcia, Gerryann Agovino,
Markie Post, Sherry Corday, Rose Fahey, Judy
Angel, Sheri Disney, Debbie Eaton, Tamara IliescuNancy Davis and
LaToya Jackson

Mel B and Bruno Tonioli

Nicky Yassini, Brandy Navarre,
Alyson Marmur, Nancy Davis, Lynn PalmerDavid Burtka, Neil Patrick Harris,
Penny and Rod Stewart

Blake and Brook Davenport

Guest with Lea Thompson
and Nancy DavisMichael and Iris Smith and
Barry and Arlene HirschfeldMark Burg, Byron Allen and
Shainaz BurgNancy Davis and
Brandon DavisMark Locks, Nancy Davis
and Konrad LehJennifer and Michael
GardnerShane Hendryson
and Dana DavisDave and Nicole Whitmore,
Nick and Cindy Locke

Ken and Brooke Lande

Matt Rosler, Maggie Knutsson,
Kurt Knutsson, Jennifer BryanAlexander and Lindsay Davis and
Amber Schoneweis

Cat Deeley



Guests with Katie Brass



Kellie Pickler

Jason Davis and
Nancy DavisMarg Helgenberger
and GuestTaio Cruz, Nancy Davis,
Mariella and Isabella RickelParris Mullins, Dawne Czarny,
Joanne Reyes, Paul RadfordJennifer Veal and
Elizabeth Stanton

ms health tips and resources

iPhone Apps for MS

1. MS Journal: developed for individuals or caregivers that are assisting with injections for MS. The Journal is easy to setup and gives you a countdown timer with optional reminders to make it easier to remember to take your medication and see where and when it should be taken.
2. MSA -- MS Self-Care Manager: a self-care application for the multiple sclerosis community from the Multiple Sclerosis Association of America; organize your health records
3. MedImage Cases: MedImage Cases™: a new eTextbook, is a series of 26 biweekly MRI case presentations, providing audio commentary from renowned MS experts of the MRI—both conventional and non-conventional forms—to be used as a tool to measure disease activity, disease progression, and response to therapy, and guide practical therapeutic approaches. Clinicians can then translate this knowledge into successful personalized treatment strategies for patients with MS.

Each case is peer reviewed and offers CME/CE credit to neurologists, IM specialists, family practice/PCPs, nurses and nurse practitioners, physician assistants and pharmacists who interact with and are involved in the management and treatment of patients with multiple sclerosis.

Top 5 Reads for MS

- 1) The Can Do MS Guide To Lifestyle Empowerment in paperback and e-book versions at most major bookstores.
- 2) Despite MS to Spite MS: By Jennifer and Dan Digman
- 3) Lean On Me: By Nancy Davis
- 4) Overcoming Multiple Sclerosis: An Evidence-Based Guide to Recover: By Professor George Jelinek
- 5) Healing Multiple Sclerosis: Diet, Detox & Nutritional Makeover for Total Recovery: By Ann Borochoms

For more info visit: <http://www.msactivesource.com/ms-yoga>

MS One to One™

Aubagio, a once-daily oral therapy approved by the FDA for relapsing forms of MS. If you have been prescribed this therapy by your doctor make sure you sign up for the Aubagio support program brought to you by MS One to One™,

Genzyme will provide you with personalized information and help during your treatment. Once you've signed up, you'll have access to personalized support including dedicated support from an MS One to One™ Nurse and commercial co-pay and financial assistance programs for AUBAGIO® (teriflunomide). You will also have access to web-based support:

- Tools to help you track symptoms, talk to your doctor and build your wellness knowledge
- Emails with information on what you may expect from AUBAGIO
- Exclusive articles, podcasts, and videos on positive approaches to living with MS

Resource: Genzyme website

Dance if You have MS!

Dance integrates various brain functions, increasing brain-body connectivity and making it a compelling alternative therapy for people with MS. Dance simultaneously involves kinesthetic, rational, musical and emotional processes. Fluid Movement work involves training the mind to feel inside the body while moving in one's own creative, fluid way. In the process, you strengthen your concentration and get more connected to your own body while hooking up the circuits between your brain and the different parts of your body!

Sensation tracking is another method useful for pain management. For more information on this technique and/or if you would like to see a video of how these two techniques work, Sensation Tracking and Fluid Movement, please go to www.movingfromtheinside.com.

Additional Therapies for Relapsing MS

Acthar® Gel is also approved by the FDA to treat MS relapses and has been used as an alternative to corticosteroids for more than 30 years. This may be helpful for individuals who are not able to tolerate the side effects of steroids, who have found that previous treatments were not effective, or who may have difficulty getting timely medical support for IV infusions. Studies suggest that the effectiveness of Acthar Gel is similar to corticosteroids.

Acthar contains a highly purified form of the adrenocorticotropin (ACTH) in gelatin. It is given once daily for two to three weeks and is injected either into the muscle or under the skin. This is then absorbed slowly into the bloodstream. Acthar works differently than corticosteroids by helping the body to produce its own natural steroid hormones that reduce inflammation and aid in recovery.

Other therapies include plasmapheresis (plasma exchange or "PE") and intravenous immunoglobulin (IVIG). Neither of these is approved by the FDA specifically for MS relapses, but either may sometimes be used for individuals who are experiencing a severe relapse and are not responding to other treatments.

With PE, blood is taken from the patient, cleansed of potentially toxic elements, and returned to the patient. IVIG therapy uses human immunoglobulin, an antibody derived from the blood of healthy donors. With both of these therapies, more studies are needed to determine their individual effectiveness.

For more information, please visit <http://www.acthar.com>

MS Genetic Component

By Dr Pierre-Antoine Gourraud, PhD MPH

The genetic component of MS has long been established by looking at familial recurrence of MS and in particular concordance rate in twins.

Over the past years, a series of worldwide efforts have been coordinated to increase the number of markers investigated for their potential role in MS susceptibility. These studies have confirmed a central role for the immune system in MS. The number of region of the genome positively identified to contain genetic variant associated with MS have now dramatically expanded the roster of MS susceptibility genes. For more than 30 years, only the role(s) of the MHC region was identified in MS, and the associations of the HLA genes (the genes that are looked at for transplantation because they determine most of our tissue compatibility) with MS have been continuously refined and better modeled since then.

Advances in technology together with novel models for collaborative across research groups have enabled the discovery of more than 50 non-HLA genetic risk factors associated with MS. The discovery of additional susceptibility genes highlights the need for summary metrics of the disease-specific genetic assessment of patients at the individual level.

While previous genetic discoveries were necessarily derived from population based studies, it is now possible to focus on single patients by computing summaries of their individual genetic risk factors. Defining a genetic profile of individual patients is unfortunately not powerful enough to predict MS, but it may help understanding who has more MS associated genes which could ultimately yield to new hypotheses about the role of genetic and disease progression or response to treatment.

(GENETICS continued on Page 16)

MS and Your Mood 24/7

By Dr. Adam Kaplin, Johns Hopkins

What was your mood like one week ago? Two weeks? Four? If you're like most people, you have a tough time remembering what your mood was like a even a few days ago. But if you or your loved one is combating depression, this information could mean the difference between successful treatment or merely basing treatment decisions on erroneous information which would be tantamount clinically to running in circles. Psychiatrists typically ask a patient to keep a written record of their daily mood between office visits, but very few patients (approximately 10%) actually remember to do so with any regularity. Therefore, most individuals must rely on their memory to recall and track their own mental health status over time. To many patients and healthcare professionals, including Dr. Adam Kaplin, a neuropsychiatrist at Johns Hopkins University School of Medicine, this process seemed illogical and imprecise. Dr. Kaplin became frustrated with this problem, and he tried to envisage a way he could improve his patient's ability to provide reliable and accurate. The answer, he found, was simple and in the pocket or handbag of nearly every patient – a cellular phone – and Mood 24/7 was born.

Mood 24/7 is a free, online mood tracking service invented and co-developed by Dr. Kaplin in cooperation with Remedy Health (formerly Health Central). Unlike paper mood charts, a patient signs up for Mood 24/7 online, and he or she designates when to receive daily SMS text prompting them to rank their mood on a scale of 1 (low) to 10 (high). The patient texts back a number and has the option to type more specific details (e.g. events which may have impacted their mood that day, changes in medication, amount of exercise) in an additional notation. These records are immediately sent to secure, HIPAA compliant servers that store and maintain each patient's virtual mood chart. The mood chart can be accessed online at mood247.com, which is accessible via a password-protected login. Healthcare providers or family members can be added to an individual's "trusted circle" to view their online mood charts and check in on their progress. If a healthcare provider is part of this trusted circle, he or she can also make comments directly on to the mood chart to provide feedback. And because Mood 24/7 combines an online virtual mood chart combined with automated daily SMS texting, it can be used with any cell phone and not just smart phones because no apps are involved.

The benefits of the straightforward daily texting record created by Mood 24/7 are beyond measure. A Mood 24/7 chart can be viewed online during office visits to use as an accurate record of mood fluctuations or stability between visits. It is essentially an electronic diary (with patient's daily entries), combined with an electronic health record (produced by each of the patient's care providers entering or copying and pasting in their assessments, plans and recommendations. Speaking with a patient about his or her mood chart is an extremely useful tool to discuss behavioral patterns and help the patient devise strategies to manage their mental health. Psychiatrists can use a patient's Mood 24/7 chart when either determining efficacy of a previously prescribed medication or making changes in the type or dose of medications when treating mood disorders. Over 10,000 people have signed up for Mood 24/7 since its inception, and adherence is 80% on average for all active users. This free tool makes patients feel engaged in their own health care, and patients report that it feels like someone cares about their well being every day when they receive the Mood 24/7 text. Increasing the knowledge of healthcare providers and improving the feelings of patients is a win-win, and the potential for this tool to be developed in other disciplines of healthcare is limitless. Mood 24/7 has allowed healthcare professionals to modernize and advance the way they track and treat patients with mood disorders. Sign up for this confidential, simple, and free service today at www.mood247.com!

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 2012 as well as research study summaries from our newly awarded 2013-2014 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:

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



Interactions of microglia and axons: Studying the interactions of microglia and axons by imaging them in real time: 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 tech-

nologies 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,
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 γ -secreting Tbet⁺Foxp3⁺ Tregs compared to healthy controls. Our data indicate that Treg reprogramming to a newly described Th1-type of IFN γ +Foxp3⁺ Tregs may play an important role in the pathogenesis of MS.

We have performed high throughput screening technologies to obtain a several molecules that are specifically involved in Th1-Treg generation.

The support of the Race to Erase MS will be helping us to characterize this subset of molecules and study their implication in the defective function observed in regulatory T cells from patients with Multiple Sclerosis. The ultimate goal of this project is define new therapeutic targets that restore the defect in peripheral tolerance in MS patients.

Pierre-Antoine Gourraud Ph.D M.P.H.
Department of Neurology, University of California San Francisco



Risk variant in MS: Discovery of risk variant in multiple sclerosis (MS) is unfolding at an unprecedented pace. A generation ago, only one susceptibility gene

(HLA-DRB1) was known, and no disease-modifying treatments (DMT) were available. By 2012, over 60 genomic regions have been found to be unequivocally associated with MS risk. Research on the well-known genomic region HLA-DRB1 includes in-depth studies of the associations of multiple genetic variants with susceptibility, disease severity and response to treatment. We are thus facing a new scenario: the discovery of additional MS gene-variants of moderate effects intensifies the need for summary metrics of the individual's MS-specific genetic configuration. If we can accurately model a summary of MS genetics and combine this with pathophysiology, immunology,

and personalized therapeutics, we will be able to effectively understand the heterogeneity of the genetic architecture of the disease.

Now, we can analyze the individual combination of genetic risk factors of a single patient. We have developed such an integrative approach to the genetics of MS: the MSGB, an optimal mathematical model that computes the individual genetic load of patients, according to the latest validated genetic association signals. It summarizes how a large number of genetic markers interact in MS patients and their families in the published mathematical model Multiple Sclerosis Genetic Burden (MSGB; Gourraud et al., 2011, AoN). MSGB is a step toward translating research into clinically relevant endpoints of MS expression.

The trans-disciplinary and translational interest of the MSGB score resides in its capacity to integrate genetic and eventually non-genetic contributions to MS risk. Integrating genetic research data into a single analytical framework will unify medical practice with cutting-edge genetic research, and pave the way to inform and personalize therapeutic decision-making in MS. By profiling MS patients with mathematical methods, we embrace the complexity of MS genetics making the exponentially growing wealth of information in the field, more accessible to scientists, physicians and patients.

1st Year YI Grant Recipients:

Anna Barsukova-Bell, PhD, MS
Department of Neurology
Oregon Health & Science University



Role of Ca²⁺ in grey matter damage: Recent findings reveal that cortical grey matter lesions occur commonly in MS and suggest that abnormalities in grey matter can better explain physical and cognitive decline in MS patients than white matter abnormalities. Specifically, neuronal and axonal degeneration within cortical grey

matter appears to be an important determinant of permanent disability in MS and a major pathogenic mechanism in progressive forms of MS. There is a tremendous need to development neuroprotective therapies for MS and development of such treatments should be driven by our understanding of the mechanisms underlying axonal degeneration in the disease. We investigate two critical mediators of axonal degeneration in grey matter: oxidative stress and resultant elevations of axoplasmic Ca²⁺. Using in vivo model and cranial window imaging technique we investigate real-time axonal changes in response to oxidative stress in cortical grey matter. Understanding Ca²⁺ dynamics in grey matter axons during stress in vivo would provide new insight on the mechanisms of damage and create a basis for testing Ca²⁺-regulating neuroprotective approaches.

Shiv Saidha, MD, MRCPI
Assistant Professor of Neurology, Johns Hopkins University School of Medicine



Non-traumatic disability: MS is the leading cause of non-traumatic disability in adulthood in the developed world. Although MS is classically defined as an inflammatory demyelinating disorder of the central nervous system, axonal and neuronal degeneration (neurodegeneration) are also clinically important pathologic hallmarks of the disorder. In fact, numerous studies have shown that disability in MS correlates best with neurodegeneration, and therefore it is no surprise that in recent years there has been growing investigation to determine the mechanisms underlying neurodegeneration in MS, the impact of neurodegeneration in MS, as well as the development of neuroprotective agents, or even potentially neurorestorative agents, that may combat neurodegenerative processes in MS.

Critical to the success of such endeavors is the necessity to be able to measure neurodegeneration, and indeed neuroprotect-

tion, in a precise and objective fashion in vivo in MS. MS has a predilection to affect the anterior visual system both clinically and subclinically, such that virtually all MS patients demonstrate optic nerve lesions at post-mortem. Demyelination and inflammation within the optic nerve result in retrograde degeneration of the constituent fibers of the optic nerve. These fibers are derived from the inner-most layer of the retina, called the retinal nerve fiber layer (RNFL), and the axons which comprise the RNFL are derived from ganglion cell neurons (which are located in a layer below the RNFL termed the ganglion cell layer). Thus MS related optic nerve pathology results in thinning of the RNFL and ganglion cell layer (GCL).

Our group has been utilizing optical coherence tomography (OCT), a non-invasive, precise, cheap, reproducible, easily repeatable and well tolerated imaging technique to quantitatively and qualitatively investigate in-vivo changes in retinal axonal and neuronal sub-populations in MS. We have employed non-conventional OCT techniques, in particular OCT-segmentation, which allow us to quantify each discrete retinal layer of the macula in MS patients. Through our work, we have shown that GCL thickness may be an ideal candidate outcome measure in trials of neuroprotection, and even neurorestoration. Moreover, we have shown that with this technique, that the eye is truly a window into the global MS disease process. For example, patients exhibiting disease activity (such as relapses, new T2 lesions on MRI, new contrast enhancing lesions on MRI) or even disability progression during the course of follow-up have the highest rates of GCL thinning. In addition, we have also found that primary retinal neuronal mechanisms of pathology in deeper layers of the retina (such as the inner and outer nuclear layers) may be operative in MS, and that such processes may not necessarily relate to optic nerve pathology or demyelination. Along these lines, thicknesses of the RNFL and GCL appear to correlate best with gray matter volume in MS, while thickness of the

(SHIV continued on Page 12)

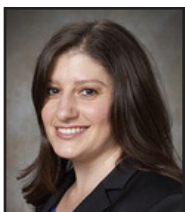
highlights from the lab, new grant receipts continued

(SHIV continued from Page 11)

inner nuclear layer in MS seems to correlate mostly with T2 lesion volume. Interestingly, we have shown that pathology within the inner nuclear layer at baseline in MS seems to predict the subsequent development of relapses, new T2 lesions on MRI, new contrast enhancing lesions on MRI, as well as disability progression.

These studies not only inform us of potential outcome measures for tracking neurodegeneration in MS and monitoring neuroprotective effects, but also further our understanding of the pathobiological underpinnings of these processes in MS. The support of the Race to Erase MS is essential for us to continue our work to unravel the basis of neurodegeneration in MS, to identify novel outcome measures for measuring neurodegeneration, and ultimately for the successful identification of effective neuroprotective and neurorestorative agents.

Christina Azevedo, MD, MPH Assistant Professor in Neurology Yale School of Medicine



Cortical thinning in MS: MRI plays a very important role in clinical trials in multiple sclerosis because it can offer a way to measure the severity of the disease and the response to treatment. A major issue in MS research currently is the lack of a robust MRI marker for the progressive phase of the disease. Cortical thickness is a promising MRI marker for this phase and can be reliably measured using high-resolution MRI scans and sophisticated software.

With support from the Race to Erase MS, we will begin to analyze cortical thickness on a large scale, which has not been done previously in MS. We will analyze over 2700 MRI scans that were collected over five years from a group of over 500 MS patients. We will be able to identify the location(s) and extent of cortical thinning

across the spectrum of MS severity, and we will see the relationship between cortical thickness and clinical markers of MS. We anticipate that this information will be an important step toward testing cortical thickness as a marker in MS clinical trials.

Jennifer Graves Assistant Professor of Neurology in the UCSF Adult and Pediatric MS Centers



Genetic Risk: There is strong evidence for vitamin D and exposure to Epstein-Barr virus (virus that causes mono) as risk factors for MS.

As environmental factors, these are potentially modifiable. Genetic risk is also important in multiple sclerosis, with the strongest known genetic risk factor for MS affecting immune function. As the majority of people with low vitamin D levels and exposure to common viruses do not develop MS, it is important to understand how genes may modify the influence of the environment.

The next frontier for MS care is identification of early markers of future severity. As newer therapies become available, some with concerning side effects, patients will require personalized treatment based on such markers. My work focuses on how MS-related genes interact with the environment to affect relapse rate in multiple sclerosis. Our preliminary work suggests that genes do enhance the effects of vitamin D levels causing increased relapses in children with MS.

With support from the Race to Erase MS we plan to extend our findings to study new genes and viruses in larger group of patients. We are using cutting edge genetic and viral technologies with collaborations with eminent scientists.



Pilot Study Summaries 2013-2014: Support for a focused research project that is novel and will unravel new aspects of MS.

David Hafler, M.D. Chairman, Department of Neurology Yale School of Medicine



How about "Salt: a Culprit in MS" Genome-wide association studies have identified numerous genetic associations between common SNPs and risk of autoimmune diseases, some of which are shared between these diseases. However, MS is not just due to genes, but instead results from untoward interactions between genetics and the environment. We recently showed that increased salt concentrations dramatically boost the induction of the inflammatory T cells (Th17 cells) that are believed to cause MS. The Th17 cells generated with high-salt display a highly pathogenic inflammatory T cell. Mice fed with a high-salt diet develop a more severe form of the animal model of MS. It was of interest to observe that analysis of genes induced by NaCl are markedly enhanced among the genes that cause MS. With support from the Race to Erase MS, we will directly investigate whether high salt diets represent one of the underlying environmental causes of MS by measuring salt intake in relationship to disease severity. We will also explore whether the specific biochemical pathways induced by a high salt diet can be targeted to develop new treatments with MS.

Brett T. Lund, Ph.D. Assistant Professor Neurology University Southern California



Exercise and MS: In recent years, studies have shown that the brain is capable of recovering from many different types of injury. Research has also shown that this recovery can be enhanced by activities such as exercise, and also environmental

stimuli which are new to the individual. However, little is known about the effect of exercise as a treatment from multiple sclerosis (MS), in particular at the early stages of disease where there is little disability. Most MS patients have a relapsing-remitting form of the disease which in the early stages has long periods of time with very little injury. We hypothesize that this stage of MS is a very good time to treat with exercise.

Exercise has been shown to have multiple biological effects both on the brain and on the immune system, both of which are involved in the disease processes that we see in MS. Exercise causes reorganization of nerve pathways in the brain that can cause improvement and help restore function in the injured brain. Exercise also causes the growth of new cells in the brain, and the development of new connections between nerves. Finally, exercise also helps to block inflammation by activating distinct anti-inflammatory molecules.

In this proposal we want to test if exercise can change the course of disease in a mouse model of MS: our preliminary observations suggest that this may be the case. In this study we plan to expand our experiments to study the effect of exercise on the number and size of relapses, how severe the disease is, and most importantly how exercise may prevent the damage that occurs in the brain.

The symptoms of MS are caused by inflammation in the brain which triggers the loss of myelin (the sheath around the nerve fibers). We want to see if this inflammation in the brain and the demyelination that comes with it are inhibited or reversed in exercised mice. If successful, this project may have identified a way that protects the brain which does not require drugs. The results we get here will allow us to design larger studies to determine the mechanisms involved in this protection and to see if this also works in patients with MS.

Leslie Weiner, M.D.
Professor of Neurology
University of Southern California



Inhibition of activated protein C (APC) as a strategy for treatment of MS: All currently approved drugs for the treatment of MS are anti-inflammatory in nature.

They control the functions of abnormal immune cells and prevent them from entering the brain and spinal cord, where they cause damage to myelin, injure or kill brain cells and interfere with natural repair processes. Although anti-inflammatory drugs are clearly beneficial, there is a great need to develop treatments that can also protect brain cells from injury or death and subsequently, prevent neurodegeneration and disease progression.

To this end, and with the help of the Race to Erase MS, we have begun to test the possibility that a new neuroprotective drug can be developed for the treatment of MS. The drug, named 3K3A-activated protein C (3K3A-APC), provides potent protection for brain cells against injury and death in models of stroke and Alzheimer's disease. Our studies will be the first to determine if 3K3A-APC has the same effect in a well-established mouse model of MS. Since 3K3A-APC is currently being tested for safety in a phase I clinical trial in healthy human subjects, the success of our studies may provide a unique opportunity to begin designing a clinical trial in MS patients.

Nancy L. Sicotte, MD, FAAN
Cedars-Sinai



Neuroimaging in MS: The North American Imaging in Multiple Sclerosis (NAIMS) Cooperative was formed with the goal of developing sensitive, reliable imaging-based surrogates for disease progression in MS. Currently, imaging measures obtained for MS research are not standardized, so the results vary based on

the scanner, acquisition sequences, and analysis techniques used. This lack of standardization leads to increased variability in the measures and makes comparisons between studies almost impossible. With support from the Race to Erase MS, this pilot project represents the first steps of the NAIMS Cooperative, which will form the foundation for future projects. We will scan a single MS patient and a single imaging phantom at seven study sites, utilizing the best available pulse sequence for each type of scan. This initial data collection will not only serve as a test run for cross-institution imaging collaboration, but it will also result in a highly valuable dataset to enable multicenter standardization.

The results of these efforts will accelerate MS research by creating standardized imaging protocols, a centralized database, multiple analytic tools and data sharing across NAIMS sites. The pooling of data obtained using the most advanced imaging and post-processing techniques will speed the identification and validation of imaging surrogates for disease progression in MS. The NAIMS Cooperative will bring together a wide range of imaging expertise focused specifically on the study of MS.

Center Without Walls Update:

The Center Without Walls was very active in 2013, accomplishing many research projects thanks to the support of the Race to Erase MS. The Foundation is excited to fund state-of-the-art cutting edge research to Erase MS.

During this past year, the Foundation has supported six very promising junior scientists to help them establish their cutting edge research. During the coming year, the Foundation will continue supporting Drs. Dominguez, Davalos and Gourraud.

In July 2013, the Foundation began supporting two new junior scientists: Drs. Barsukova and Saidha. Dr. Dominguez at Yale is studying immune cells, aka Th1 regulatory cells that dampen inflammation

(CWW continued on Page 16)

photo gallery, continued

Race to Erase MS



Live Auctioneer, Vanessa Thanos
with Terry Thanos and Guests



Robert Knepper and
Son



Guest with David Faustino and
Bryan Carter



Catherine Bell



Nancy Davis, Amy Spitznagel,
Jimmy Dowsett II and Guest



Nicola and Chris Alpe



Anna Trebunskaya, Gleb
Savchenko, Chelsie Hightower



Guest with Jeanette Elsner
and Helen Rabbal



Amy Yasbeck



Molly O'Neil, Lyndi Hirsch and
Harriet Sternberg



Harry and Lisa Hamlin



Nancy Davis and
Erica Weinberg



Lisa Vanderpump



Claudia Curry Hill, Kelley Hill, Peter Glecker,
Dr. Emmanuelle Waubant



Nancy Davis and
Alyson Marmur



Becky Hernreich
and Guest



Guest with
Melissa Rycroft



Guest, Steven Cojocar,
Guest, Nick Chavez



Christine Devine and
Sean McNabb



Matt Sorum and
Guest



Shane Hendryson, Nancy Davis, Dana Davis,
Shane O'Neil, Paul Mesher, Michael Atmore



Josh Hopkins



Judy Nowland, Janelle Chenier, Liz Williams,
Suzanne Fisher, Robyn Williams



Linda Gray



Tawny Sanders, Nancy Davis,
Ina Soltani



Daisy Fuentes



Shaun Robinson



Kelly Osbourne and
Matthew Mosshart



Bruce Perlmutter, Nancy Davis, Terrence Jenkins



Kathy and Rick Hilton, Kim Richards



Ziggy Marley and Orly Marley



Dr. Henry McFarland, Nancy Davis
and Dr. Adam Kaplan



Barry Sloane and Guest



Tracy and Katie Danza



Marcy Taub, Nancy Davis,
Ellen Robinson, Debbie Lustig, Iris Smith



Sara Gilbert



Dave Windfield and
his wife Tonya



Daniel and Alison Petrocelli



Zoey Deutch



Carmel and
Ryan Geise



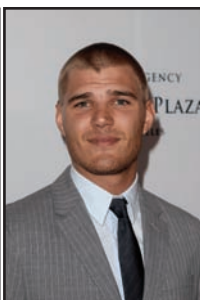
Jamie Winkler and
Paige Hemmis



Kristin Cavallari



Joyce Rey, Laurel Barrack,
Nancy Davis



Chris Zylka



Matthew Mosshart, Kelly Osbourne, Lisa and
Jack Osbourne, Rod and Penny Stewart



Lawrence Rhee, Jeff and Meg O'hare,
Bret Barker



Howard and
Pam Levine



Alex Schultz and Guest



Brian Alpert, Kiki MacMillan,
Drew Anderson



Bella Thorne



Ken Rickel, Arnie Cohen, Nancy Davis, Karen Cohen,
Barbara Davis, Isabella and Mariella Rickel



Alexis Knapp

Diet and MS

By Dr. Vijay Yadav, OHSU

People with MS often wonder what led them to have MS and if there is any connection between what they consume from the environment and their getting MS.

Another question that I get asked commonly by patients in my MS clinic is whether there is a diet that can help decrease the disease activity or disability from MS. The answers to these questions are not easy as the science behind the connection of diet and MS remains controversial.

The most well-known work about role of diet in MS comes from Dr Roy Swank, who was a neurologist and treated people with MS in an era where there were no available disease modifying therapies. Dr Swank's work suggested that high saturated fat diet such as present in animal based food products may have some relationship to MS activity and disability. He conducted few studies looking at effects of "Swank diet" in MS that however are scientifically not well-accepted due to methodologic concerns.

"Swank diet" in essence is a low fat diet consisting primarily of total daily fat consumption to be less than 20% of total caloric intake along with intake of fish and fish oil. More details about this diet are available online as well as in published books authored by him. Other studies involving diet intervention in MS have not been conclusive and are limited by small number of patients and short duration of the studies.

We at Oregon Health & Science University have recently completed a one year study looking at the effects of a low fat diet devised by Dr John McDougall on brain imaging (Magnetic resonance imaging, MRI) in 61 people with relapsing remitting MS and are in the process of analyzing the data at the time of this writing.

There is also emerging data that diet and lifestyle related illnesses such as high

blood pressure, high blood fats, diabetes and heart disease may have adverse effect on MS related walking disability. Though not sufficient at present time for concrete recommendations, these data do suggest possible role of healthy lifestyle including a healthy diet in MS management.

In our MS clinics, we recommend people to follow a low fat diet as well as do regular exercise and to follow effective stress management techniques for a better living with MS.

(CWW continued from Page 13)

in the brain and unraveling the mechanisms that control these cells.

Dr. Davalos at UCSF is sorting out how a protein of the blood, aka fibrinogen, is stimulating brain scavenger cells thereby contributing to the inflammation and nerve cell injury seen in MS scars.

Dr. Gourraud at UCSF is advancing how we can analyze more efficiently large genetic sets of information to advance our understanding of MS.

Dr. Barsukova-Bell at OHSU will examine the onset, progression and morphology of nerve cell degeneration in cortical grey matter and lesions in a mouse model of MS called EAE. An association between neuronal degeneration and calcium elevation, as well as neuroprotective effects of lowering calcium in neurons in cortical grey matter, will be investigated.

Dr. Shiv Saidha at Hopkins will utilize a novel technology called optic coherence tomography (OCT), which can very precisely measure the health of nerves in the back of the eye called the retina and study how they degenerate. He will examine whether OCT measures of nerve damage in the eye can predict nerve damage in other parts of the brain.

Four pilot research grants were also awarded to highly exciting and innovative research projects. Dr. Hafler at Yale hypothesizes that chronic high salt intake in a genetically susceptible host may function as a trigger for the development

of MS. He will investigate the role of high salt in manipulating immune functionality in patients.

The next project funded is the North American Imaging in MS (NAIMS) study. It is a collaborative effort led by Dr. Sicotte at Cedar-Sinai including MRI experts from the Race to Erase MS Center Without Walls and other colleagues. The aim of this project is to develop a standardized MS imaging protocol across multiple centers in North America and sensitive, reliable imaging based surrogates for disease progression that will accelerate MS research.

The third study sponsored by the Foundation is led by Dr. Lund at USC who will test if exercise can change the course of disease in a mouse model of MS. He plans to study the effect of exercise on the number and size of relapses, how severe the disease is and most importantly how exercise may prevent the damage that occurs in the brain.

The fourth research study is Dr. Weiner's at USC. He plans to test a drug that works on multiple disease processes that are observed in MS, including inflammation, changes in blood vessel functions and neurodegeneration. This drug is known as human 3K3A-APC, and is modified from a protein called activated protein C (APC).

All these talented scientists and doctors share the results of their research at Race to Erase MS symposium which foster the blossoming of promising junior researchers in order to one day cure MS.

(GENETICS continued from Page 9)

All these recent advances are encouraging current larger effort that will probably add dozens of new regions to the current list.

However, with a large proportion of the disease heritability still unaccounted for, focused studies are now tracking the identification of causal alleles in each of these regions that will help to elucidate the biological mechanisms underlying MS.

Cognitive Function Overlooked with MS?

By Dr. Adam Kaplin, Johns Hopkins

Patients with Multiple Sclerosis (MS) can experience a wide variety of symptoms due to the disease's effect on the brain and spinal cord that can be easily overlooked or even misunderstood as being somehow unrelated to inflammation. Some may experience fatigue, others might feel pain, while still others might suffer from depression. There is a disconnect between what a neurologist can see on a standard MRI scan of the brain and these sets of symptoms. Nevertheless, the inflammation and attacks on the brain can often lead to problems with attention, learning and memory that, while they can be easily overlooked during a routine clinic appointment, can often have a profound impact on people's ability to work and take care of family business.

Approximately half of all individuals with MS experience learning or memory issues, termed cognitive impairment. Among the most common cognitive functions that are negatively affected in people living with MS are: 1) the slowing of the speed with which their thinking and problem solving ability proceed, 2) the trouble recalling information that has not been rehearsed many times, such as remembering people's names or phone numbers, or the experience of not recalling a word or phrase that one is looking for during a conversation, and 3) the difficulty in juggling several things that require attention all at the same time.

Although it is rare for MS patients to experience overt dementia, a global loss of cognitive function often observed in patients with Alzheimer's disease, MS-associated cognitive impairment substantially impacts the lives of MS patients and their families. Cognitive impairment is the leading predictor of departure from the workforce in MS patients. Individuals with impaired cognitive function due to MS tend to participate less frequently in social activities. Cognitive impairment due to MS also places significant strain on a caregiver, who can misunderstand the forgetfulness as being willful or simply

the result of not inattention due to lack of interest.

There are currently 10 FDA-approved treatments for MS, but none, unfortunately, target cognitive impairment. Research is being done to change this. Recent studies at the Johns Hopkins School of Medicine spearheaded by Kristen Rahn in my group in collaboration with Barbara Slusher of the Hopkins Brain Science Institute have demonstrated a correlation between cognitive function and brain levels of N-acetylaspartylglutamate (NAAG), an abundant protein that mediates signaling between neurons. Although human studies of this chemical messenger await the development of a drug safe for human testing, we found that elevating the levels of NAAG in an animal model of MS using a laboratory drug resulted in a two-fold improvement in learning and memory compared to untreated animals. Based on this published study in the animal model of MS there may be hope for the development of a drug treatment for MS cognitive impairment on the horizon, with luck a matter of years rather than decades away.

Until a drug is available to prevent or reverse MS-associated cognitive impairment, there are things that individuals with MS can do to strengthen their learning and memory abilities. Compensation for lost cognitive function due to neuronal damage by applying learned strategies and employing technological aids can restore a significant amount of function.

Beyond behavioral compensatory strategies, there is evidence that the prevention or lessening of cognitive impairment can be achieved by utilizing uninjured brain regions known as cognitive reserve. While it is impossible to change your passive cognitive reserve (i.e. premorbid intelligence), there are many ways to improve your active cognitive reserve. Active cognitive reserve is strengthened by activities that keep the brain active and fit, such as physical exercise, playing a

musical instrument, learning a new language, socializing with friends, volunteering, and reading educational newsletters like this one.

A 2013 study demonstrated that MS patients with high active cognitive reserve experienced much less severe physical (e.g. spasticity, mobility impairment) and cognitive (e.g. forgetfulness) symptoms of MS compared to those MS patients with low active cognitive reserve. Another 2013 study reported that MS patients who regularly participate in recreational activities had protection against brain shrinkage, called atrophy, while MS patients who stopped participating in recreational activities experienced more atrophy.

Therefore, we encourage you to participate in social activities and seek out tasks and activities that require active engagement of your brain. It could improve your cognitive function and physical disease symptoms, and it will certainly enhance your quality of life!

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.

Social Security Disability Benefits

Steps you need to know to apply!

Multiple Sclerosis is recognized by the Social Security Administration (SSA) as a condition that qualifies for social security disability benefits. When applying for benefits due to multiple sclerosis the first step is the initial application process. It is important to understand that only approximately 30 percent of applicants are approved for benefits during this stage. To increase your chances of being approved during the initial application process, you need to provide the SSA with medical evidence that demonstrates that your case of multiple sclerosis meets the conditions set forth in the SSA's Blue Book.

Qualifying for Benefits:

Multiple sclerosis is covered in Section 11.09 of the SSA's Blue Book. This Blue Book contains a listing of all of the conditions that could qualify an individual for Social Security Disability benefits. Having a condition that is listed in the Blue Book, however, is not enough to qualify you for benefits from the SSA. You must be able to prove that your condition meets the requirements that have been set forth under the listing that pertains to your condition. According to Section 11.09 of the Blue Book, in order to qualify for Social Security Disability benefits due to multiple sclerosis you must be able to prove:

- You suffer from a disorganization of motor function in two extremities that has resulted in chronic disturbance of your gross and dexterous movements or gait; or
- You suffer from visual impairment that results in vision of 20/200 or less; or
- You suffer from mental impairment that prevents you from maintaining full-time work activity; or
- You suffer from reproducible fatigue of motor function with substantial muscle weakness when performing repetitive activity, which is demonstrated on physical examination and results from neuro-

logical dysfunction in the areas of the central nervous system that are known to be pathologically involved by the multiple sclerosis process.

When submitting your initial application for Social Security Disability benefits, you will want to provide medical evidence documenting that your condition meets the above-mentioned criteria. If you cannot obtain such medical evidence because your case of MS does not meet these guidelines but still prevents you from performing gainful work activity, you will need to fill out a residual functional capacity form and try to obtain SSDI or SSI benefits based on a vocational allowance.

Filing a Disability Appeal:

If you are denied benefits during the initial stage of the application process, you will need to appeal the SSA's decision. The first stage of appeals is referred to as a Request for Reconsideration.

The second stage of the appeal process is called a disability hearing. This is when you will have your case heard by an administrative law judge and it is also the part of the appeal process that grants you the greatest chance of being awarded the benefits you are applying for. While it can take two years or more to actually obtain a hearing date, the good news is that nearly two-thirds of applicants who attend a hearing receive their disability benefits as a result of said hearing.

The Services of a Social Security Disability Attorney:

When applying for Social Security Disability benefits it is crucial that all of your application forms are filled out properly and that you submit as much medical evidence as possible with your application. Because it is essential that you have all of your paperwork in perfect order, you may want to consider retaining the services of a Social Security attorney. These lawyers work with these cases on a daily basis and understand what the SSA needs to see in order to approve your case for

benefits. Statistics have shown that applicants who go into the process with proper legal representation are more likely to be awarded benefits than applicants who do not.

Source: Security Disability Help (www.socialsecurity-disability.org), which is an informational website on the Social Security Disability program. Contact the Rocky Mountain MS Center: Thanks to a generous grant from the Multiple Sclerosis Foundation, the Rocky Mountain MS Center was able to develop an educational program to help people through the application process by offering a one-on-one consultation with an expert. For more information, contact the center at 303-788-4030 ext. 103.

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 Race to Erase MS Gala in Los Angeles on May 2, 2014!

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!

Call 310-440-4842 for more information.

Orange
you Happy to
Erase MS

ERASEMS.ORG

SHOP ONLINE TODAY

and propel us one step closer to finding a cure for multiple sclerosis.



Look out for new products in 2014!

The Race To Erase MS Is 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. It Is The Hope Of The Foundation That In Addition To Combating MS Through Research In A Clinical Environment, An Increased Awareness Will Be Created By Educating The Public About This Mystifying Disease. 310-440-4842

RACE TO ERASE MS

Photo: Mike Windle



1875 Century Park East, Suite 980
Los Angeles, CA 90067

Address correction requested

Non-Profit Org.
U.S. Postage
PAID
Los Angeles, CA
Permit No. 5605

Race to Erase MS is a tax exempt 501(c)(3) charitable organization. We do not endorse any company, product or organization referenced in this publication.

TRIBUTE CARD PROGRAM

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

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

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

SAVE THE DATE

**21st Race to Erase MS Gala
"Love to Erase MS"
Friday, May 2, 2014**

Hyatt Regency Century Plaza
For more information please call 310-440-4842 or visit www.erasems.org

**2014 MS Forum and Expo
Saturday, May 3rd
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.

2013 Presenting Sponsors Thank you for your generous support!



HYATT REGENCY
CENTURY PLAZA
LOS ANGELES