

#### **Contents** Winter 2014

Tommy Hilfiger 2015 "Medal of Hope" Honoree / p. 3

MS Forum and Expo / p. 4

North American Imaging in MS update on project / p. 5

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

Health Tips & Resources / p. 8

Exercise and MS / p. 9

Center Without Walls Program Update / p. 10

9 Ways to Overcome MS Burnout / p.17

Personal Stories / p. 18-19



@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

### 21st Annual "Love to Erase MS"

Early this spring on May 2, 2014, we celebrated our 21st Race to Erase MS at the Hyatt Regency Century Plaza. Our honoree and "Medal of Hope" recipient Dean Singleton is an inspirational spirit and a role model to everyone with multiple sclero-

Hosts for the evening were Jordin Sparks, Randy Jackson, Shaun Robinson, Shemar Moore and Keegan Allen. The evening also included a live auction called by Howie Mandel and Jack Osbourne, during which lucky bidders walked away with items including unique St. Regis hotels, a week charter of a gorgeous yacht to the Bahamas and an Aston Martin.

Race to Erase MS continued its legacy of incredible musical performances this year, including Grammy Award-winning



Natalie Cole and Steven Tyler

artist and musical icon Steven Tyler, who was introduced by friend and fellow American Idol judge, Randy Jackson, and sang an incredible five-song set which included Tyler and Aerosmith's best hits "Walk This Way," "Cryin'," and "Jaded." Tyler spoke about his admiration for his musical inspiration, Nat King Cole, and Natalie Cole joined Tyler on the stage for an impromptu duet of Aerosmith's "Don't Want To Miss A Thing," a truly unique moment. Tyler then closed the set with a moving rendition of "Dream On."

Longtime supporter Shemar Moore introduced music legend Natalie Cole, while sharing with the audience that his date for the night was his mother, a MS survivor. Cole graced the stage to sing "Everlasting Love," and a medley from her latest CD Natalie Cole en Espanol, which included "Oye Como Va." CeeLo Green, who opened the show, got the crowd on their feet and rocked out to his hit "Forget You." Green stated how grateful he was to be asked to be a part of the night.

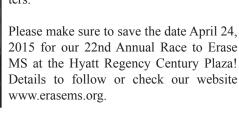


Nancy Davis, Steven Tyler and Natalie Cole

Guests could not stop talking about the spectacular floral arrangements generously donated by Mark's Garden. Everyone commented on their extraordinary beauty. Mindy Weiss, well known event designer, created a lively auction atmosphere. Guests couldn't leave without picking up the amazing Race to Erase MS gift bag so generously donated by Tiger J. Sweet E's Bakeshop spoiled guests with scrumptious treats to top off the evening.

We would like to thank our amazing presenting sponsors Hyatt Regency Century Plaza, Aston Martin and Associated Television International for their generous support. Our event sponsors were truly instrumental in making the Race to Erase MS an electrifying evening. Thank you to Bianchi Winery,

Svedka Vodka, Neo North America, New Belgium 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 presen-





"Lean on Me" Finale

PAGE 2 2014

## **Message from Nancy Davis**

**President and Founder** 



It is truly incredible to witness the historic strides that have been made in MS research as we approach our 22nd year of the Race to Erase MS. There are now 11 FDA approved therapies on the market to help stop the progression of this debilitating neurological disease. Just a short

two decades ago there was nothing for anyone diagnosed to rely on for hope.

Our Center Without Walls program has continued to flourish with the most brilliant of proposals being funded by the Race. Our Young Investigators have become the corner stone of our accomplishments as we see the seed money we have given them blossom into NIH funding. We would also like to thank our Scientific Advisory Board (SAB) Dr. Luanne Metz who has needed to move on due to research obligations for all of her hard work and dedication to helping select the best of scientific proposals for funding by the Race. And we welcome our new member to the SAB, Monica J. Carson, Ph.D, who is Professor and Chair, Division of Biomedical Sciences at the University of California Riverside, School of Medicine. She will be joining Dr. Henry McFarland and Dr. Daniel Reich who comprise our brilliant team of our SAB who are the key to ensuring every dollar raised is only going to the most cutting-edge MS research to help bring us one step closer to a cure.

We are doing a very exciting and ground breaking survey with Everyday Health to explore factors involved in MS diagnosis and progression, and we would love to have your help to spread the word about this survey. Please visit www.everydayhealth.com and click on erasems. Results of this survey will come out in February 2015.

We are thrilled to be honoring Tommy Hilfiger with our Medal of Hope award at our 22nd Race to Erase MS gala on April 24, 2015. He has been a true hero and a friend to everyone with multiple sclerosis and he has been instrumental to the success of the Race to Erase MS. I hope everyone can join us for this fabulous evening celebrating an amazing human being.

Wishing everyone love, health and happiness in the new year and looking forward to great hope in 2015. Together we will win this Race to Erase MS!





Everyday Health and the Race to Erase MS have partnered to explore factors leading to diagnosis and disease progression. Help us expose commonalities among people with MS. If you have been diagnosed, take our survey at everydayhealth.com/erasems. With your help we can better understand this disease. Study findings published February 2015 at everydayhealth.com and erasems.org.





# Our Race to Erase MS Honoree! Tommy Hilfiger 2015 "Medal of Hope"



Tommy Hilfiger

We are so honored to recognize Tommy Hilfiger at our 22nd Annual Race to Erase MS event on April 24, 2015 at the Hyatt Regency Century Plaza.

I truly can't think of anyone more deserving of our Medal of Hope award. He has been a loyal partner from the inception of this quest to find a cure for MS which was thought to be an impossible dream.

Tommy Hilfiger and I met over twenty years ago when he was just becoming a household name and I was just coming to terms with my new diagnosis of MS. I had just founded the Race to Erase MS and and our Center Without Walls program. He had a deep concern for his sister with multiple sclerosis and we met through a

friend and immediately had a synergy that blossomed into an incredible partnership to find a cure for this devastating neurological disease. I know we wouldn't be where we are today without his creative vision, hard work, determination and extreme generosity.

Below is a brief biography on this great man we are so honored to recognize at our 22nd Annual Race to Erase MS:

For over 25 years, Tommy Hilfiger has brought classic, cool, American apparel to consumers around the world. Under Hilfiger's guidance, vision and leadership as Principal Designer, The Tommy Hilfiger Group has become one of very few globally recognized designer brands offering a wide range of American-inspired apparel and accessories.

Hilfiger introduced his first signature collection in 1985 by modernizing button-down shirts, chinos, and other time-honored classics with updated fits and details. The relaxed, youthful attitude of his first designs has remained a distinctive hallmark throughout all of Hilfiger's subsequent collections. Today, the Tommy Hilfiger brand continues to bring preppy, all-American classics to consumers around the world. The business has grown from a single menswear collection in 1985 to a global lifestyle brand achieving over US \$6.4 billion dollars in retail sales in 2012. There are over 1,450 Tommy Hilfiger stores, in over 90 countries on 5 continents.

We look forward to honoring Tommy Hilfiger, an incredible role model who has brought us one step closer to finding a cure for MS. We look forward to celebrating with everyone April 24, 2015 so make sure to mark your calendars! For more information call 310-440-4842.



1999 - Tommy Hilfiger, Rebecca Romijn, Nancy Davis



Tommy Hilfiger and Nancy Davis at the 2002 Race to Erase MS event

#### **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

Monica J. Carson, Ph.D,
Professor and Chair,
Division of Biomedical Sciences
UC Riverside, School of Medicine

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. Johns Hopkins Hospital

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

Nancy Siccotte, M.D. Cedars-Sinai

Emmanuelle Waubant, M.D., University of California, San Francisco

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

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

Center Without Walls Medical Director Emmanuelle Waubant, M.D., University of California, San Francisco PAGE 4 2014

## **MS Forums and Expo**

#### Free and open to the public

Our semi-annual program is free and open to the public and we welcome you, your family, and friends to attend this unique opportunity to ask questions, receive resources and information, and to speak directly to top MS research doctors from around the country. The forum takes place twice a year in the Spring and Winter at Hyatt Regency Century Plaza. Please make sure to check our website for details or request to be added to our email list for updated information. A special thank you for the generous support of Everyday Health and Associated Television International for making our forums accessible to those who cannot attend.

Our forums this year covered topics including depression and anxiety, promising therapies for MS, and regeneration and repair. Our 2014 Honoree Dean Singleton and 2013 Honoree Jack Osbourne joined the Spring panel as guests and shared their personal experience with MS lending advice and inspiring hope to those battling the disease. Board Member Claudia Curry Hill who chairs our forums is also the forum moderator.

At our health and wellness expo in the Spring, guests enjoyed resources and interactive activities available to them prior to the forum. We thank all of our wonderful Expo partners for their valuable participation and all they do to support those who have MS. Companies such as EMD Serono, Biogen, Genzyme, and Questcor passed out information on different MS therapies and treatments. Karman Healthcare and MS Genie showcased their advanced medical equipment to aid those with physical and mobility disabilities. Bed of Nails shared their amazing acupressure mats and pillows that can help MS patients relieve tension and pain, and Chandra Scofield Wellness presented the benefits of acupuncture. We also want to thank Raw Elemental, Noosa Yoghurt, Yogabilty and The UCLA Marilyn Hilton MS Achievement Center and Wellness Champions, Canine Companions and Liv360. We also would like to extend a warm thank you to the Hyatt Regency Century Plaza, Sweet E's, and Clementine's for their invaluable donations to this very important educational opportunity.

Our Race to Erase MS Spring MS Forum and Expo will take place on April 25th, 2015 at the Hyatt Regency Century Plaza at 10:00 AM. 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.











Guests enjoy the resources provided by our invalubale Expo Partners and Panelists



Mckenzie Hoffman, Loni Anderson, Deidra Hoffman, Megan Hoffman



Matt Rosler and Kurt Knuttson



David Osmond and Claudia Curry Hill



Dean Singleton and Nancy Davis



Lyndi Hirsch and Dana Davis



Karen Kruegar and Cindy Locke



Nancy Davis and Jack Osbourne



Dr. Leslie Weiner, Dr. Daniel Pelltier, Dr. Emmanuelle Waubant, Jack Osbourne, Dean Singleton and Nancy Davis, Dr. Adam Kaplin, Claudia Curry Hill, Dr. Dennis Bourdette, Dr. David Hafler



Dr. Leslie Weiner (center) and forum quests



Dr. David Hafler speaking on panel



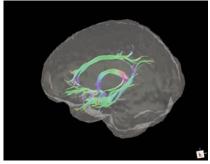
Panel and Audience

## North American Imaging in MS (NAIMS)

#### **Exclusivley funded by Race to Erase MS**

Magnetic resonance imaging (MRI) is a powerful tool used to study disease activity in multiple sclerosis (MS) and plays a central role in clinical trials of promising new therapies. Standard MRI measures inflammation, but 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 hold promise as readouts for trials of new therapies that promote remyelination or neuroprotection.

So why aren't these new techniques a routine part of clinical trials? The answer is that most trials involve many sites with different MRI scanners 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. As a result, most clinical trials still use the



Advanced MRI Image

"lowest common denominator"- that is, the scans are done at the lowest level that can be achieved across sites. This is the main reason why newer imaging approaches remain in the exploratory phase despite evidence suggesting 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 semi-annual Symposium. Current NAIMS core members and centers include: Rohit Bakshi (Harvard), Peter Calabresi (Johns Hopkins), Ciprian Crainiceanu (Johns Hopkins), Beth Fisher (Cleveland Clinic), Roland Henry (University of California-San Francisco), Jiwon Oh (Johns Hopkins/University of Toronto), Daniel Pelletier (Yale), Daniel Reich (National Institute of Neurological Disorders and Stroke), Bill Rooney (Oregon Health Sciences University), Nancy Sicotte (Cedars-Sinai), Taki Shinohara (University of Pennsylvania) and Jack Simon (Oregon Health Sciences University).

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; and (3) bring together a range of imaging expertise focusing on the study of MS.

Pilot project: In July 2013, the Race to Erase MS awarded funds to the NAIMS Cooperative for the first NAIMS pilot project. The goal of this project is to create a standardized MRI protocol using advanced imaging approaches that can be used across centers in patients with multiple sclerosis. By pooling expertise, each site will benefit from the knowledge of the others, and unlike previous studies, this MRI protocol aims to use 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 will raise the bar for MS imaging research in North America.

Since funding began the NAIMS group has met regularly and has made significant progress on the pilot project. In December 2013 the NAIMS meeting took place in conjunction with the Race to Erase MS Fall meeting. A half-day symposium was held on the campus of Cedars-Sinai that included invited lecturers from California Institute of Technology. Protocol details and imaging sequences were proposed for testing and a Microsoft Sharepoint website was developed to serve as a repository for all NAIMS pilot related documents and logistical planning. With the support of the American College of Radiology, a web-based imaging archive has been created allowing for easy sharing of data across all centers.

At the May 2014 NAIMS meeting, participants reviewed imaging sequences obtained across all sites. Members achieved consensus on the optimal versions that make up the pilot imaging protocol. Each site can now download the optimized sequence and test them on a healthy volunteer. Institutional Review Board approval for the overall study was granted which will allow our test MS patient to travel to each of the seven NAIMS imaging sites. These visits will begin in January 2015 with completion by the end of March.

The NAIMS Cooperative will meet again at the American Academy of Neurology in April 2015 to review results, plan analyses and manuscript preparation. Overall the pilot has led to development of vital infrastructure that will serve as the basis for many exciting projects to come. The strong foundation made possible by Race to Erase MS pilot funds will allow us to advance the field of advanced imaging to test the next generation of MS therapeutics and beyond.

Source Note: Summary provided by Dr. Nancy Sicotte, Cedars-Siani

PAGE 6 2014

#### photo gallery: 21st Annual Race to Erase MS







Kelly Osbourne and Nancy Davis



Steven Tyler and Natalie Cole



Rickel Family, Barbara Davis and Nancy Davis



Tommy and Dee Hilfiger



Brenda Richie, Randy Jackson, Lynn Palmer, Nancy Davis



David Foster, Howie Mandel



Harry Hamlin, Mark Locks and Guest



Randy Jackson, Steven Tyler, Nancy Davis



Kathy and Rick Hilton



Steven Tyler, Dean Singleton



Jory and Greg Phillinganes, Nancy Davis



Cynthia Ott, James Coleman and Patrica Cox



CeeLo Green



Linell Shapiro, Harry Hamlin, Julie Opperman



Marilyn Wilson and Shemar Moore



Lexy Rose and Daniel Ziff



Shane Hendryson, Dana Davis



Ghada Irani, Tamar Manoukian



Deb and Bill MacMillan



Guest with Elena Pikor, Ina Soltani and Guest



Carmen Electra



Nancy Davis, Lynn Palmer



Paul Palmer, Jon Lovitz



Alessandra Ambrosio



Leslie Ziff, Lexy Rose, Jake Sanders, Carol Strone



Sherry Corday and her Son



Tawny and Jerry Sanders



David and Laura McKenzie



Anna Trebunskaya Tracey Fentem, Victoria Page, Michele Davis







Dana Davis, Nancy Davis, Barbara Davis



Randy Jackson, Steven Tyler, Keegan Allen, David Osmond



Keegan Allen



Ava Dyborn, Isabella Rickel, Mariella Rickel, Steven Tyler



Kurt Schmalz, Victoria Page



Johnathon Schaech and Guest, Guest, Garcelle Beauvais, Guest with Byron Allen



Lisa Rinna, Ken Rickel, Harry Hamlin



Cheryl Burke, Lisa and Jack Osbourne



Steven Tyler, Dean Singleton, Adam and Adrienne and Paige Singleton



Guest with Mary Conner



Debbie Lustig, Nancy Davis, David Osmond



MacMillan Family and Guests



Nancy Davis, Ina Soltani



Nancy Davis, Brandon Davis





Jordin Sparks Mary Hausman, Glenn Bianchi, Teri Hausman



Karen and Arnie Cohen, Brooke Lande, Nancy Davis, Jimmy Lustig



Margaret Nagle and Helena Simpson



Addie Martini, Carina and Cindy Locke, Karen Kruegar



Jason Davis, Nancy Davis



Lea Thompson



Jennifer Gardner and Guests



Ryan and Deana Cimorelli



Mariella and Isabella Rickel



Alexis Berman and Suzanne Berman



Nicholas Berman, Joshua Rosenzweig, Paul Berman, Grant Berman, Ken Sullivan

PAGE 8 2014

#### ms health tips and resources

#### **Pediatric MS**

Founded by Elin Phillips, PMSA is a 501c3 organization whose goal it is to connect parents of kids with MS, provide quality of life services and opportunities to families with a child, teen, or young adult with MS, and to raise awareness about pediatric MS. Examples of services and support include financial assistance, social opportunities, parent to parent networking, educational and informational resources from pediatric MS specialists, psychologists, teachers and educational professionals, collaborative work with several MS organizations, and more. Through our fundraising, PMSA will be working to expand and improve upon our programs to help parents and caregivers gather the tools they need to provide their children with the best quality of life while living with MS.

http://www.pediatricms.org/

#### **About Pediatric Multiple Sclerosis:**

Childhood MS may represent up to 10% of all MS cases. Although the clinical profile of MS appears similar to that seen in adults, several features may differ and specific issues arise in children. Younger patients with MS are more likely than adults to have seizures, brainstem, and cerebellar symptoms. Children with MS may have fewer T2 hyperintense areas on MRI scans, therefore not meeting MRI criteria established for adults.

Pediatric MS is similar to adult MS in the kinds of symptoms that occur. MS varies from person to person so there is no 'standard' set of symptoms for MS. However we know that common symptoms of MS include numbness or tingling in various parts of the body, weakness of one or more parts of the body, walking difficulties, dizziness, fatigue, visual blurring, and occasionally double vision.

Patients may also have a symptom called Lhermitte's phenomenon, in which they feel electrical tingling or shocks down their back, arms or legs when they bend

(PEDIATRIC continued on Page 16)

## **Biogen Idec's PLEGRIDYTM Approved for Relapsing MS**

The U.S. Food and Drug Administration (FDA) has approved Biogen Idec's PLE-GRIDY<sup>TM</sup> (peginterferon beta-1a) as a new treatment for people living with relapsing forms of multiple sclerosis (RMS). PLEGRIDY is administered subcutaneously just under the skin once every two weeks. The FDA approval of PLEGRIDY is based on one year results from ADVANCE, a placebo-controlled clinical trial which involved more than 1,500 people living with MS. In the study, PLEGRIDY was shown to significantly reduce important clinical and imaging measures, including slowing the progression of disability and decreasing the number of relapses and brain lesions. The company provides a variety of support services for patients and caregivers, including financial assistance programs, through MS ActiveSource®. For more information on PLEGRIDY, including prescribing information. go PLEGRIDY.com.

## Genzyme gets FDA Approval on LemtradaTM

Genzyme, a Sanofi company, announced mid November that the U.S. Food and Drug Administration (FDA) has approved LemtradaTM (alemtuzumab) for the treatment of patients with relapsing forms of multiple sclerosis (MS). Because of its safety profile, the use of Lemtrada should generally be reserved for patients who have had an inadequate response to two or more drugs indicated for the treatment of MS. "Lemtrada demonstrated superior efficacy over Rebif on annualized relapse rates in the two studies which were the basis for approval. A comprehensive risk evaluation and mitigation strategy (REMS) will be instituted in order to help detect and manage the serious risks identified with treatment." said Genzyme President and CEO, David Meeker. For more detailed information visit: GENZYME.com

#### **Memory Games and MS**

Why are memory games so beneficial? In part, it's because people who participate in mind-stimulating tasks create a cognitive reserve that benefits them later in life. And if you are currently having specific cognitive problems, certain types of brain games can help. For example, games or exercises that involve rapidly taking in information may improve your mental speed if you have slowed information processing. So talk with your MS doctor about your symptoms, and give the following games a try to stimulate your mind and help keep your edge.

My Brain Games, a free online suite of games developed specifically for the MS community.

Another great website is Cognifit.com. "Some common cognitive problems that can affect people with MS are impaired processing speed; short-term memory and attention problems; skills like problem solving, reasoning, and mental flexibility; visual perception problems; and difficulty remembering words," says Tracy Carrasco, OT/L, MSCS, an occupational therapist at the Orlando Health Multiple Sclerosis Comprehensive Care Center of Central Florida.

The games at Cognifit.com work to improve memory and other cognitive impairment issues. You can even download apps on your smartphone or tablet to take these games with you when you're on the go to stave off MS symptoms.

Also squencing games like dominos, corssword puzzles and jigsaw puzzles.

To research and find more brain excerising games visit Everyday Health for more resources and information at:

http://www.everydayhealth.com/multiple-sclerosis-pictures/brain-games-forms.aspx#03

## **EVINE Live Supports the Race**

We are so thankful to EVINE Live, a digital retail store, for their incredible support of Race to Erase MS. As part of Nancy Davis' Peace & Love Jewelry line, EVINE Live has created a limited edition Invicta Baby Lupah watch that will be featured during EVINE Live's 2015 Valentine's weekend launch event. The watch will be available in either gold or silver tone bezel, with seven beautifully colored leather straps. A generous donation has been made by EVINE Live to the Race in celebration of their premiere event. Customers are invited to shop, share and smile with EVINE Live as they discover new, exciting brands. See ad below and make sure to check our website (www.erasems.org), EVINE Live's website (evine.com), and/or follow us on Facebook for details and dates of the show! Nancy Davis will personally be on air to celebrate EVINE Live and promote this commemorative watch. Much thanks to our new partner, EVINE Live!



## **Excercise and MS**By Dr. Rebecca Spain, OHSU

Exercise is without a doubt good for people with MS. Yet, questions about exercise are some of the most frequent I get during MS clinic: What type of exercise is best for MS? Why do my MS symptoms reappear when I exercise? Will too much exercise hurt me? Will it make my MS worse? What can I do to increase my endurance? I discuss these questions in the office every day.

The first thing I do is congratulate people for understanding the importance of exercise in promoting both short-term and long-term health. In fact, by avoiding vascular risk factors such as high blood pressure and high cholesterol through exercise and other healthy habits, people with MS can slow disability even better than by taking MS drugs. Therefore I strongly encourage all people with MS to find an exercise routine that works for them as a necessary part of their medical management of MS.

While there is no one best type of exercise for MS, a general rule of thumb is to combine cardiovascular exercise with a stretching routine that matches each individual's abilities, opportunities, and goals. For those who can walk, bike or run, go for it! Stationary bicycles, water aerobics, and chair exercises can help those with balance, strength, or coordination issues. Classes help those of us who need the external motivation to exercise and/or who appreciate the social component. A physical therapist can help design a home exercise and stretching routine based on your specific needs and abilities.

Some find that prior MS symptoms reappear or worsen when exercising such as blurry vision, tingling, or muscle spasticity; the same symptoms go away after a rest. This is known as Uhthoff's phenomenon, named for a 19th century neurologist who understood that the nervous system did not work well when overheated. While not damaging the nervous system, the effect may limit exercise due to the natural rise in body temperature.

Those unable to tolerate the heat should choose a sport with a colder temperature option such as swimming in a colder pool, walking or biking in the cool of the morning, or training in an air conditioned gym. A cooling vest that lowers the core body temperature can be of critical value for those with heat intolerance for both in and out of doors.

Another option is to exercise for shorter but more frequent periods to avoid increasing body temperature. This strategy may also help those with poor exercise endurance. Endurance can also be addressed by a physical therapist but needs to be specifically requested. In addition, dalfampridine is an FDA-approved medication that can improve walking speed and for some, exercise endurance. When it works, it can really make a difference in a person's ability to exercise.

Finally, I must stress the importance of a daily stretching and strengthening routine for MS. I see in the office again and again how those who successfully make it a life habit reduce or eliminate the need for medications for pain and spasticity, both symptoms frequent and challenging for people with MS. In summary, exercise promotes a long a healthy life for people with MS, reduce disability, and does not cause injury to the nervous system. The key is to find the routine that is fun, personalized, and that can become a lifelong habit.

PAGE 10 2014

#### 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 2013 as well as research study summaries from our newly awarded 2014-2015 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:

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



Role of oxidative stress 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. Our pilot data suggest that 24 hour exposure to oxidative stress in vivo leads to degenerative morphology in cortical neurons. Understanding Ca2+ dynamics in grey matter axons triggered by oxidative 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



Optical Coherence
Tomography in MS:
MS is the leading cause
of non-traumatic disability in adulthood in
the developed world.
Although MS is classi-

cally 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 endeavours is the necessity to be able to measure neurodegeneration, and indeed neuroprotection, 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 gagnlion 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 OCTsegmentation, 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, the eye is truly a window into the global MS disease process. For example, patients exhibiting disease activity (such as relapes, new T2 lesions on MRI, new contrast enhancig 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 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 neuroproetective 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 re-

sponse to treatment. A major issue in MS research 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 have begun to analyze cortical thickness on a large scale, which has not been done previously in MS. We have processed over 3000 MRI scans that were collected over five years from a group of over 500 MS patients. We have begun to look at which deeper brain structures are atrophied and how they change over time,

and soon we will begin to analyze cortical thickness. 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 finding a surrogate marker for use in MS clinical trials for the progressive aspect of the disease.

#### 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
multiple sclerosis. 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.

#### 1st Year YI Grant Recipients:

#### Oleg Butovsky Ph.D. Instructor in Neurology, Brigham and Women's Hospital Harvard Medical School



Mechanism of regulation of inflammation by microglia in EAE:
Microglia are resident myeloid-lineage cells in the CNS and function in the maintenance of nor-

mal tissue. Microglia can become activated and/or dysregulated during disease, and thus affect disease progression or resolution in MS.

Understanding the biology of microglia is a challenge due to absence of markers and genetic signatures that distinguish them from hematogenous infiltrating macrophages with identical morphologies. Recently, we identified a unique molecular microglia signature which provides insights into microglial biology. We hypothesize that resident microglia have different phenotypes during different stages of CNS inflammation including phenotypes that facilitate recovery and phenotypes that perpetuate chronic inflammation.

The focus of our studies is to characterize resident microglia and how they regulate and/or participate in CNS damage during neuroinflammation and whether CNS inflammatory disease such as MS can be treated by specifically targeting and modulating microglia in a way that restores their unique molecular properties.

The support of the Race to Erase MS will help us to identify the mechanism of regulation of inflammation by microglia in the EAE animal model of MS. Moreover, it will help to design new therapeutic strategies for the treatment of MS.



PAGE 12 2014

#### highlights from the lab, grant recipients continued

Pilot Study Summaries 2014-2015: Support for a focused research project that is novel and will unravel new aspects of MS.

Peter Calabresi, M.D.
Professor of Neurology at the Johns
Hopkins School of Medicine,
Director of the Johns Hopkins Multiple
Sclerosis (MS) Center,

Dir. of the Div. of Neuroimmunology



Phase 1 study of intrathecal rituximab in progressive MS: Recently, it has been discovered that in multiple sclerosis (MS) immune cells may survive

in the coating around the brain and spinal cord called the meninges. These clusters of immune cells are called lymphoid follicles and are more common in progressive forms of MS. These follicles are associated with increased demyelination of the grey matter of the brain and likely play a role in worsening of the disease.

Injecting medications into the spinal fluid is called intrathecal (IT) administration and can be done in cancers in order to better target cells in the meninges. This has been done with a monoclonal antibody drug called rituximab or anti-CD20 to deliver the medication directly where it is needed in brain cancer.

We are testing whether giving IT rituximab in progressive MS may disrupt these follicles and slow progression of MS. In this pilot study, we propose to use a new MRI method to identify these follicles and determine if the therapy makes them go away. This novel trial could be beneficial to patients with progressive MS, who are in need of effective therapies, by establishing the safety of IT rituximab in progressive MS.



David Hafler, M.D.
Gilbert H. Glaser Professor of
Neurology and Professor of
Immunobiology; Chair, Department of
Neurology. Yale University School of
Medicine



Environmental and genetic factors that contribute to the development of MS:

Recent advances have elucidated many environmental and genetic

factors that contribute to the development of MS. While genome wide association studies have identified over 100 genetic variants associated with an increased risk of developing MS, very little is known as to how these variants alter immune responses resulting in predisposition to disease.

Cytokines are critical factors in regulating immune responses and blocking specific cytokines has proven effective in treating many autoimmune conditions. However, several of the therapies that were expected to be effective in MS, including TNF-α and IL12/23 blockers, have proven ineffective in clinical trials. In fact, blockade of TNF-α was found to exacerbate MS and may result in new onset MS in patients being treated for other autoimmune conditions. Of note, many of the genetic variants associated with increased risk of developing MS fall within genes responsible for determining how immune cells respond to cytokines including TNF-α and IL12/23, suggesting that alterations in cytokine responses may underlie disease susceptibility. These alterations may also help to understand the failure of cytokine blockade in MS and help to tailor personalized medicine based on rapid genetic screens for individuals that may be amenable to specific treatments. The support of the Race to Erase MS will help us to understand how changes to cytokine signaling pathways impact the development of disease and suggest novel therapeutic targets for the treatment of MS.

#### Ellen Mowry, M.D., M.C.R. Assistant Professor of Neurology, Johns Hopkins University



Mitochondrial
Dysfunction in Multiple
Sclerosis: Does Vitamin
D Alter the MS
Metabolic Signature?:
In multiple sclerosis
(MS), some scientists

think that inflammation caused by the disease damages tiny "cellular power plants," called mitochondria, which exist in most of the cells of the body. When the mitochondria don't function properly, particularly in the nervous system, there can be damage to the nerve cells themselves. Several published and unpublished studies have suggested that mitochondrial damage might be the link between relapsing MS, thought to be caused by inflammation, and later risk of progressive MS, thought to be due to nerve damage. In this study, we will assess if there is evidence of abnormal mitochondrial function in people with MS compared to those without the disease. We will also assess if supplementation with vitamin D, which may impact mitochondrial function, does lead to evidence of better mitochondrial function.

#### Samuel J. Pleasure, MD/PhD Professor, Department of Neurology, UCSF



Mapping the synaptic partners of oligodendrocyte precursor cells:
In multiple sclerosis (MS) demyelination by the immune system leads to damaged areas

where loss of myelin contributes to neuronal dysfunction. All approved therapies for MS focus on blunting the autoimmune attack on myelinating cells. Recently many have focused on trying to develop approaches to treat MS either facilitating repair of myelin or protecting the nervous system from the consequences of chronic demyelination. This has led to a great deal of focus on the ability of a special set of progenitors in the nervous system, oligo-

dendrocyte precursor cells (OPC), to respond to demyelination. OPCs are a group of cells that divide and differentiate into oligodendrocytes (the cells that make myelin) during brain development. OPCs are also present in the adult brain and they expand their numbers and migrate to areas of myelin injury and attempt to repair the injury by producing new oligodendrocytes and myelin. Understanding the process of OPC production, expansion, migration and differentiation is likely to provide novel ideas for assisting CNS repair after injury. One of the most unusual recent aspects of OPC biology is the realization that OPCs receive synaptic inputs from neurons. The primary idea in the literature is that OPCs receive synapses from axons so that they can monitor the firing frequency of axons and that this may control the timing of OPC differentiation and myelination. In this proposal we are using a novel technique that allows infection of a highly defined group of cell types with a virus that is then transferred backwards across synapses to label cells upstream. This will allow us to determine how many neurons make a synapse with an individual OPC, where these neurons are located and whether they are of a particular type. The Race to Erase MS Funds will directly support our pilot studies to understand the anatomic complexity of OPC-neuron synapses to allow us to develop new strategies to enhance myelin formation and repair.

Rebecca Spain, MD, MSPH Assistant Professor, Neurology Oregon Health & Science University Staff Physician, Portland VA Medical Center



Aerobic exercise to improve brain metabolism in MS:

There is increasing interest, research, and development of neuroprotective and neurorestorative

therapies for multiple sclerosis (MS). Aerobic exercise, a candidate neuroprotective therapy, leads to clinical improvement in people with MS as well as morphologi-

cal changes in areas of memory in rat that suggest neurogenesis. brains Mitochondrial dysfunction is a postulated mechanism by which neurodegeneration occurs; therefore supporting mitochondria with aerobic exercise may provide a neuroprotective benefit. However unlike measuring mitochondrial function in muscles by using a VO2max stress test, capturing mitochondrial function in the brain has heretofore been unavailable by traditional MRI techniques. Dr. Bill Rooney at the OHSU Advanced Imaging Resource Center has developed a novel phosphorous 31 MR spectroscopy imaging (31P MRSI) technique thought to reflect mitochondrial ATP (energy) stores on a voxel by voxel basis in both gray and white matter brain areas. The advantage to quantifying mitochondrial metabolic activity through 31P MRSI instead of customary brain atrophy measures, is that it will allow us to identify areas of the brain at risk for early cell death prior to the atrophy that occurs later. By identifying at risk areas, we can then determine the metabolic effects of our developing neuroprotective and neurorestorative therapies on the health of the brain.

This study will test the hypothesis that a structured aerobic exercise program will improve brain mitochondrial function as measured by an increase in 31P levels using the novel 31P MRSI technique. In order to do so, 5 MS patients will undergo an intensive cardiac training program for 8 weeks. Five MS patients matched for sex and baseline cardiac fitness will simultaneously participate in a stretching program of similar frequency and duration. All subjects will be tested for aerobic fitness using a VO2max stress test and brain phosphorous levels using the 31P MRSI technique prior to and following the respective programs.

The Pilot Award will allow us to determine if exercise improves mitochondrial brain function using 31P imaging. Once established, we will conduct a large-scale trial of an exercise intervention to determine the magnitude and duration of the neuroprotective benefit of exercise on brain health in MS.

#### **Center Without WallIs Update**

The past year has been terrific for The Center Without Walls. Many exciting novel research projects are ongoing and several outstanding junior faculty are developing cutting-edge research thanks to the support of the Race to Erase MS.

During this past year, the Foundation has supported seven very promising junior scientists to help them establish their cutting-edge research. In July 2014, the Foundation has started to support one new junior scientist, Dr. Oleg Butovsky (Harvard). This doctor is studying immune cells, aka microglia to understand better their very important role in MS such as regulation of inflammation and damage in the brain, but also to unravel the mechanisms that control these cells.

During the coming year, the Foundation will continue supporting Drs. Shiv Saida (Hopkins), Barsukova (OHSU), Graves (UCSF), and Azevedo (Yale) for their second year of young investigator award. Dr. Barsukova-Bell at OHSU examines 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 examines whether OCT measures of nerve damage in the eye can predict nerve damage in other parts of the brain.

Dr. Graves is studying factors in the environment that together with genes contribute to higher frequency of MS relapses. This is a novel area of research as the interactions between genes and environment in MS are poorly understood and some may be amenable to treatment. Dr.

(CWW continued on Page 16)

PAGE 14 2014

#### photo gallery, continued







Steve Hash, Ally Hilfiger



Daisy Fuentes



James Thompson, Elizabeth Stanton, Betsy Smith, Devon Werkheiser



Nancy Davis, Tommy and Dee Hilfiger



Erika Tucker Weinberg, Nancy Davis



Zach Bauer, Cammy MacMillan, Law Jones, Brett Hagan, and Callie Klebanoff



Steven and Kelly Erickson, Ryan and Carmel Giese



Dove and Jeff Rudman



Bill MacMillan Jr., Alexis MacMillan with Guests



Witney Carson



Nao and Arlene Hirschfeld, Ken and Judy Robins, Barry Hirschfeld



Linell and Robert Shapiro



Stephanie Perkins, Corby McCarthy



Shaun Robinson



Thora Birch and Tommy Hilfiger



Shainaz and Mark Burg



Brandon Blair, Claudia Curry Hill, Matt Rosler, Maggie and Kurt Knutsson



Paul and Alba Radford



Karina Smirnoff, Candace Cameron Bure



Alexis, Sari and Grant Berman



Matthew and Aileen Clarke



Jordan Cohen, Nancy Davis



Mark and Mindy Leonard



Michael Gunter, Jenna McConnell, Connie Genova, Susie Hotz, Meredith Hotz Olson, Ralph Bellizzi



Brenda Richie, Guest with Cynthia Ott, Nancy Davis, Bonnie Pfeifer



Karen and Arnie Cohen, Dina Cohen



Patrick and Jennifer Gaydos, Debbie Mendelson, Dan Silverberg



Mariella and Isabella Rickel dancing with dance troup



Barry Sloane and Guest



Pamela Lynch, Jennifer Daris, Kimberly McKinney, Jade Dillion Feilke



Beth Littleford



Cyrus Wilcox, Clementine Ford



Amy Vida and Michea Fisher



Helen Randall, Guest, Jeanette Elsner, Guest



and her Mother



Francesca Capaldi Deidra Hoffman, McKenzie Hoffman, Megan Hoffman, Loni Anderson



Dr. Leslie Weiner and Guests



Mark Held, Nancy Davis, Richard David



Mark Burg and Bruce Perlmutter



Guest with Patrica Cox, Cynthia Ott, James Coleman, Nancy Davis



Anna and Ally Romano





Shawn King and Guest Holland Roden



Katie and Tracy Danza



Laura Vandervoort



Brian Smith, Jeff O'Hare, Bret Barker, Brandon Collyer, Chelsea Collyer



Nancy Davis, Brandy Navarre, Nicki Yassini



Ron Rosen with Guests



Cobi Jones and Wife



Christine Devine, Tamera and Adam Housley and Guest



Dr. and Mrs. Adam Kaplin



Lindsay Arnold



Guest, Lenny Steiner, Guest, Bruce Friedman, Kenny Rickel, Nancy Davis and Guest

PAGE 16 2014

#### (CWW continued from Page 13)

Azevedo has developed a project investigating the rate of thinning in specific brain regions occurring in MS with a new MRI measure called cortical thickness. She will then evaluate the effect of MS treatments on the rate of thinning in the regions thinning faster than others.

The newly developed MRI project called the North American Imaging in MS (NAIMS) is a collaborative effort led by Drs. Sicotte at Cedar-Sinai and Jiwon Ho at Hopkins including MRI experts from the Race to Erase MS Center Without Walls and other North American 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.

Five pilot research grants were also awarded this year to highly exciting and innovative research projects.

Dr. Calabresi at Hopkins will study small doses of rituximab injected in the spinal fluid as a potential new treatment strategy for patients with progressive forms of MS.

Dr. Hafler at Yale will determine how genetic variants associated with increased disease risk result in changes to immune responses and ultimately to the development of MS.

Dr. Spain from OHSU will study whether aerobic exercise will lead to an increase in energy levels in the brain, similar to what exercise does in muscles, and whether we can measure that increase in energy using a new phosphorous imaging technique.

Dr. Pleasure from UCSF will study whether connections between nerve cells and other brain cells called glial cells are important both for correct myelination of neurons during development and for remyelination after injury.

Finally, Dr. Mowry at Hopkins will capitalize on an ongoing study of vitamin D supplementation in patients with MS and healthy controls to confirm the recent discovery of an abnormal profile in mito-

chondria, i.e. the energy producers in cells. She will also determine if supplementation with vitamin D alters the MS metabolic signature.

Several times a year, all these talented scientists and doctors share the results of their research at Race to Erase MS symposia which foster the blossoming of promising junior researchers in order to one day cure MS.

#### (PEDIATRIC continued from Page 8)

their neck forwards. Sometimes people notice hesitancy when they try to urinate or may find that 'when they have to go, they have to go'. There is no way to predict which symptoms one person might develop. The usual course of MS is to have periods of time where things are relatively stable, followed by times when, over a few days or weeks, new symptoms occur or old symptoms worsen. This relatively rapid worsening is known as an exacerbation (also known as an attack, or a relapse). In others with MS, there may be a tendency to progress in that symptoms gradually worsen over time (months to years).

## Join Our Virtual Race to Erase MS!

Help 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 April 24, 2015!

SIGN UP TODAY! http://virtualrace.kintera.org/erasems

Call 310-440-4842 for more information or email info@erasems.org



## **CENTER WITHOUT WALLS Collaborating Physicians**

Dr. Katerina Akassoglou, UCSF Dr. Lilvana Amezcua, USC Dr. Dennis N. Bourdette, OSHU Dr. Peter A. Calabresi, Johns Hopkins Dr. Rob Bakshi, Harvard Dr. Michele Cameron, OHSU Dr. Tanuia Chitnis, Harvard Dr. Dimitrios Davalos, UCSF Dr. Margarita Dominguez-Villar, Yale Dr. Roopali Gandhi, Harvard Dr. Wendy Gilmore, USC Dr. Pierre-Antoine Gourraud, UCSF Dr. David Hafler, Yale Dr. Roland Henry, UCSF Dr. Jiwon Ho, Johns Hopkins Dr. Halina Hoffner, OHSU Dr. Adam Kaplin, Johns Hopkins Dr. Eve Kelland, USC Dr. Brett Lund, USC **Dr. Ellen Mowry,** Johns Hopkins Dr. Gopal Murugaiyan, Harvard Dr. Kevin O'Connor, Yale Dr. Jorge Oksenberg, UCSF Dr. Daniel Pelletier, Yale Dr. Samuel Pleasure, UCSF Dr. William Rooney, OHSU Dr. Nancy Siccotte, Cedars-Sinai Dr. Jack Simon, OHSU Dr. Rebecca Spain, OHSU Dr. Arthur Vandenbark, OHSU Dr. Arun Venkatesan, Johns Hopkins Dr. VJ Yadav, OHSU Dr. Emmanuelle Waubant, UCSF Dr. Leslie Weiner, USC Dr. Howard Weiner, Harvard Dr. Scott Zamvil, UCSF

#### 2014-2015 Young Investigators

Dr. Christina Azevedo, Yale Dr. Anna Barsukova-Bell, OHSU Dr. Oleg Butovsky, Harvard Dr. Jennifer Graves, UCSF Dr. Shiv Saidha, Johns Hopkins

## 9 Ways to Overcome MS Burnout

#### Courtesy of EverydayHealth.com

It isn't easy managing a disease like multiple sclerosis. The day-to-day physical and emotional demands of controlling MS symptoms like fatigue, visiting doctors and other healthcare professionals for therapy, tests, and treatments, while trying to do the normal daily activities of work and family, can leave patients feeling exhausted, overwhelmed, and burned out.

Burnout is an emotional condition marked by tiredness, frustration, and hopelessness – all resulting from prolonged stress. "Patients may be concerned about how unpredictable the disease is, what the future might bring, and how to manage all the things on their plate when they're not feeling so well," says Rosalind Kalb, PhD, clinical psychologist and vice president of clinical care at the National Multiple Sclerosis Society. "One can feel overwhelmed by the enormity of it, and not know which problem to try to solve first."

#### **Setting Manageable Goals Can Help**

Denise Belle of Knightdale, North Carolina, knows the feelings of burnout all too well. When she was diagnosed with MS 18 years ago, she was a 20-yearold college student with dreams of becoming a nurse. "I was devastated," she says. "When you're 20, you think you're invincible." After multiple relapses and trips to the hospital to try to control the spasms she was having in her hands, face, and legs, she started taking medication, began taking better care of herself, and finally faced reality. "It took me three to five years after my diagnosis to really come to grips with it and say, 'This is my life," she adds.

What helped her get through it? One thing was staying in school and being able to shift her dream of becoming a nurse to becoming a public health advocate instead – a career she still feels passionate about today. Years of graduate school work helped her set manageable goals for herself and stay focused and optimistic about her future. Helping others through her

public health advocacy work gave her a sense of purpose and put her own health problems in perspective.

"I'm a type A personality, and I love a good challenge," Belle admits. "When I was told that I might not be able to finish school because of my MS, I said 'No way! I've come too far!" Belle ended up finishing her master's degree in three years and graduating with honors. Now she works as director of community-based outreach programs for Rural Health Group, Inc. "Set your goals high," she advises. "What else is going to give you the strength that you're going to need to keep putting one foot in front of the other?"

## **More Tips for Overcoming MS Burnout**

Get your health team in place: "It's easy to look at all your symptoms and not know which one to deal with first," says Dr. Kalb. "That's why comprehensive care is so important." By working with a team of professionals – from neurologists to physical and occupational therapists – you can get help managing all aspects of your disease with the goal of slowing its course, managing whatever relapses you might have, and enhancing your function in every way possible.

#### Get support from family and friends:

In addition to your medical team, having family, friends, and fellow patients to turn to for support is crucial. "One of the biggest components of feeling at the end of your rope is a sense that you're there by yourself — and that nobody understands," says Kalb. "Having a support group can help relieve that feeling." Belle credits her mother, her boyfriend William, and her girlfriends for being there for her during her darkest times. "I can be my most vulnerable with my 'sisters'," she says, referring to a small group of friends she regularly leans on for support.

Rest, relax, and recreate. Be good to yourself by reducing the stress in your life as

much as possible and resting when you need to. "You have to listen to your body," says Belle. "When it's telling you that it's exhausted and requires rest, you have to stop and rest." In addition to rest, Belle regularly indulges in relaxing activities like gardening with her mother, watching movies with her friends, walking her dog Jackson, reading, and chilling out with her boyfriend. She also enjoys an occasional girls' night out.

Adopt healthy habits. Eating well and exercising regularly can help you feel more balanced. "There's a lot of evidence that exercise can help with mood," says Kalb. "The key is finding exercise that fits with whatever your abilities and limitations are." Belle walks on a treadmill and lifts weight for strength training when she can. "I also meditate daily for 15 minutes," she says, which helps her to manage stress and revitalize.

Allow yourself time to grieve. "Every time MS takes something away from you and requires you to do something differently or think about yourself and your life in a different way, you have to grieve, and that's normal and healthy," says Kalb. Belle admits that the hardest moments for her are the ones where her symptoms are exacerbated and she finds herself unable to do the things she loves. "I have to be pretty honest and open to the fact that not every day is going to be a good day," she says.

Become a problem-solver. With every new challenge, it's important to come up with strategies for overcoming them, one small step at a time. "We know that people who have problem-solving coping strategies do much better than people who react in a more emotional way," says Kalb. "They're less prone to depression because they have the ability to parse out the big picture into smaller bites that they can manage better."

Tap into local resources. If you need special accommodations at work or at home, reach out to the National MS Society and other patient advocacy groups to learn what resources are available to you in your community. When Belle's headaches and

(9 WAYS continued on Page 18)

PAGE 18 2014

## **Mitzvah Project Raises over \$30K**

For my Dad and everyone with MS - By Abby Katz



Abby and her Dad

My name is Abigail Katz and I am 13 years old and in the 7th grade. I live in New Jersey with my mother Stacey, my father Adam and my older sister Jordyn. We are a very close family. When I was 4 years old my father was diagnosed with Multiple Sclerosis. At that time, I really didn't know what it was but I did know that he had to give himself injections every other day and sometimes he would have trouble with his hands and get bad headaches. He never kept his illness a secret and when he gave himself his injections he would have a calendar and a diagram of a body on his sink in the bathroom. It would be my job to circle in sharpie the part of his body on the piece of paper

where he gave himself the shot and then write down the date. I was his assistant. 4 years after my father was diagnosed, his older sister was also diagnosed with Multiple Sclerosis.

As I got older I learned more about Multiple Sclerosis and the impact it had on my father. I also knew that my father had really good doctors taking care of him and how important research into new medicines and a cure for MS is. I really don't remember not knowing about Multiple Sclerosis because it's always been part of my life.

On November 1st I had my Bat Mitzvah and as part of my preparation I completed a Mitzvah Project (a good deed). I immediately knew I wanted to do something with Multiple Sclerosis and I worked with my mother doing research into different organization where I could help. I eventually picked Race to Erase MS because as a kid, I thought it was really cool how many celebrities were helping also. I was going to raise as much money as I could in the hopes that this money would help with research and to find a cure for the disease that my father, my aunt and so many others have.

In June of 2014 I held a spin event for kids in my town to raise awareness and all the proceeds raised went directly to the Race to Erase MS. In addition, I shared my fathers story via email to family, family friends and people throughout my community in the hopes that they would contribute to the Race to Erase MS. I also made bracelets which were sold in school and camp and all the kids wore them.

Not only did I educate people on Multiple Sclerosis and the Race to Erase MS, but, so far I have raised over \$30,000. I will continue raising money and awareness for the Race to Erase MS even though my Bat Mitzvah is complete. I have another Spin event



Stacey, Abby, Jordyn and Adam Katz

in the works and I'm very excited to continue my relationship with this important organization!

I know that this money will go to good use and I am confident that in my lifetime I will say I was part of the cure.

#### (9 WAYS continued from Page 17)

muscle pain became severe, for example, she submitted an ADA (Americans With Disabilities Act) work accommodations request that allowed her to work from home when necessary.

Watch for signs of depression. "Depression is very common among MS patients – more common than with other chronic disabling illnesses," says Kalb. How can you tell the difference between depression and burnout? "If you feel sad, miserable, and hopeless for days or weeks on end, without any let up, and if you lose interest in the things that used to give you pleasure and enjoyment, that's depression," says Kalb. If you think you're depressed, talk to your doctor.



**ERASEMS.**ORG

#### SHOP ONLINE TODAY

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



## **MS and Motherhood**

**By Christine Brovelli O'Brien** 



Christine Brovelli O'Brien and Daughter

When I was diagnosed with relapsing-remitting multiple sclerosis in the spring of 2013, I knew my life undeniably was going to change, not only for me, but also for my husband and daughter, who was only 22 months old at the time.

My initial fear of going blind after developing optic neuritis in my left eye has lessened somewhat now that my vision has since improved, although it will never be restored completely. And, thankfully, my mobility has not been hindered – but, oh the fa-

tigue! The level of exhaustion that comes along with MS and the medication surprised me the most, and this is coming from someone who, at the time of my flare-up last year, was teaching full-time and still adjusting to being a first-time mom! No sleep just came with the territory. Believe me, I'd had my share of sleepless nights and exhausted days.

I could compensate for poor vision with my "good eye," but what about taking care of my child with such fatigue? "Mommy needs to rest" doesn't always go over so well with a toddler, especially when that toddler translates "rest" as "reading five books" or "building a block tower" or "chasing the cats around the living room." The funny thing about life, though, is that you somehow adapt. I am the third generation in my family to have MS, and I know what can happen if you don't take care of yourself.

So, I found the courage to leave a stressful job to stay home full-time with my daughter and pursue freelance writing. Chasing after a seemingly indefatigable three-year-old is not what I would call easy, but I'm much happier. Most of the time I feel great and have a lot of energy, and on the hard days, I've developed a few tricks that help me cope ("Let's build a pillow fort and pretend we're taking a nap" seems to work well).

On those not-so-great days, I have an amazing partner in my husband, who takes over much of the childcare and household duties when he isn't at work. It was difficult at first not to feel guilty that I can't "do it all." But, I've learned that it's ok to ask for – and accept – help. Asking my husband to cook dinner even though I've been home all day does not make me lazy, nor does asking my parents to babysit my daughter so I can take a nap. It's what I need to do to stay healthy, and it's working so far. I haven't had a flare-up since March 2013, and I hope to keep it that way for a long time.

I've also discovered the strength that can be found when you open yourself up to the love and support of those around you, and it's an important lesson I hope to pass on to my daughter.

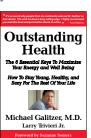
#### **Multiple Sclerosis Symptoms:**

<u>Most common early symptoms of MS include:</u> 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.

#### **Homeopathic Resource**

I'm thrilled to announce the upcoming release of a ground-breaking book that has the potential to dramatically improve your health. It's called Outstanding



Health, and was written by my good friend Dr. Michael Galitzer and bestselling author Larry Trivieri Jr. For more than 25 years, people from all around the world have sought out Dr. Galitzer be-

cause of his revolutionary approach to health that consistently helps his patients look and feel much younger. The reason his program is so effective is because of its unique combination of conventional and complementary medicine—and in particular, its focus on Energy Medicine, which addresses health at the cellular or energetic level.

In this groundbreaking book you will discover how to renew and revitalize yourself in body, mind, and spirit, so you can enjoy outstanding health at any age. Your journey begins with a new understanding of yourself as a dynamic "being of energy," and how to use Energy Medicine to detect and correct health problems long before they ever develop into physical symptoms. Then you will discover the 6 Essential Keys to Outstanding Health, and everything you need to do to incorporate them into your daily life so that you can start to look and feel fantastic. You will also discover breakthrough solutions for keeping your brain and heart healthy and youthful for the rest of your life, along with littleknown, futuristic medical technologies that are available today. Best of all, most of what Dr. Galitzer teaches you can be done on your own, empowering you to be in control of your health for the rest of your life. Read this book and create your own Outstanding Health starting now.

Do be notified when Outstanding Health becomes available early next year, visit www.DrGalitzer.com and while you're there, be sure to sign up for Dr. Galitzer's newsletter.

PAGE 20 2014



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**

## 22nd Race to Erase MS Gala "Love to Erase MS" Friday, April 24, 2015

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

## 2015 MS Forum and Expo Saturday, April 25th 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.

### 2014 Presenting Sponsors Thank you for your generous support!



HYATT REGENCY

CENTURY PLAZA

LOS ANGELES

