

SPRING 2015

NEW YORK CITY - SOUTHERN NEW YORK CHAPTER

MS CONNECTION NEWSLETTER



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PUBLICATION OF THE NATIONAL
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LETTER FROM THE CHAPTER PRESIDENT



Can you feel it? Can you see it? It's change and it's happening all around us, signaling a revitalization of our purpose here at the New York City – Southern New York Chapter of the National MS Society.

We are redoubling our efforts around our mission to do something about multiple sclerosis NOW in order to create a world free of MS.

Beginning with our range of programs and services, for people living with this unpredictable disease and their loved ones who are impacted by it, we offer an open invitation to attend educational seminars, receive employment assistance, information, and legal counseling as well as network at events for people in their 20s and 30s, and events for children, parents, couples and caregivers.

At this time of promise for what's to come, I also hope you'll join with your family, friends and neighbors to form a Walk MS team or volunteer at one of our six walk sites.

As you read this issue of *MS Connection*, get inspired by the testimonials of the individuals featured and know that together, we can empower them so they can live better lives until a cure is found.

Thank you for your support and involvement with the chapter and know that you play the most important role of all when it comes to moving us toward a world free of MS!

Sincerely,

Robin Einbinder
President



WALK TEAM "MAKE THAT CHANGE".

WALK MS 2015

SIX DIFFERENT LOCATIONS
APRIL 18, 19, 25 & 26

REGISTER TODAY AT:
WWW.WALKMSNYC.ORG

WALKING FOR A CURE

Like walking, for Shawn Harvey Roberson, life is about “balance.” Diagnosed with multiple sclerosis in 2008, just months before her wedding to GRAMMY-nominated singer, songwriter and producer Eric Roberson, Shawn, a wife, mother of two, and business woman, credits family and especially her husband with helping her cope.

“When I think of balance, and the reason that I have any, it is first because of Eric,” she explains. “To have a true partner in life like him, helps me attempt to find balance.”

“Family is the best vitamin for life,” says Eric. “No matter what you are going through, family can add strength to every step you take. Our families have helped Shawn and I tremendously from day one.”

The Robersons and their team “Make that Change” have been participants in Walk MS since 2009.

“It’s one of the strongest ways to amplify awareness,” Eric says. “Our family, friends and my staff participate every year. We try to raise as much money as possible and encourage conversations about multiple sclerosis.”

Shawn also advocates about MS and plans to increase her involvement in the chapter.



On the Cover: Shawn and Eric Roberson and their son Ryder at Walk MS.

*This issue has been brought to you by a generous grant from Biogen Idec.

CHAPTER NEWS

SAVE THE DATE!



The Dystel Memorial Golf Classic
June 8, 2015

Sunningdale Country Club
 Scarsdale, NY

Visit www.MSnyc.org for details!

ASK THE REHAB EXPERT

BEING AN ACTIVE PARTICIPANT IN YOUR REHAB PROGRAM

BY DR. STEPHEN KANTER, PHYSICAL THERAPIST, INTERNATIONAL MS MGMT. PRACTICE, DIR., ATHCARE CONSULTING AND EDUCATION

When it comes to patients with MS looking for a good therapist to provide care, many will ask for someone who knows MS. While this is a good and

proactive strategy to try to find an appropriate therapist, another strategy is developing a meaningful, functional rehabilitation goal.

The thought that people with MS can and should get as much therapy as is needed due to the nature of the disease has led to disappointment for patients, their families, therapists and even neurologists. Most insurance policies, including Medicare, limit the overall number of therapy sessions that a person will be covered for. To make the most out of the therapy sessions that are provided, patients, their caregivers and the treating therapists must be clear on functional goals that therapy can help achieve. Goals such as “getting stronger” or “walking better” are hard to truly accomplish. In some cases, this goal is redefined by a therapist in order to meet insurance requirements. Therefore, it is essential that the patient and their caregiver(s) explain what functional task/activity would be improved by getting stronger or walking better.

This active participation will allow for more effective communication between the patient and the clinician (physical therapist, occupational therapist or speech language pathologist) and better progress toward reaching the agreed upon goals. Your active involvement should also include requesting collaboration between your therapists so treatments complement each other and insurance coverage is not inadvertently overused by one specialist.

For more information email Dr. Kanter at skanter2@imsmp.org or call 201-248-9847.



KWAME ANYANE-YEBOAH

“MY BROTHER WAS DIAGNOSED WITH MS ABOUT FIVE YEARS AGO, AND I STARTED VOLUNTEERING TO DO SOMETHING TO SUPPORT HIM.”

VOLUNTEER CORNER

Kwame Anyane-Yeboah’s photography skills were honed at an early age.

“My father put a camera in my hand and asked me to take family photos. When I would go to events with him and he would always ask me to bring my camera,” he says. “It became my job from then on.”

Fast-forward to college and Kwame’s photography hobby turns lucrative.

“I got my first digital camera, a Canon, and that’s when things really progressed for me. I had friends who would photograph concerts in New York City, and they’d ask me to come with them,” he says. “One of them is now the editor of *Impose* magazine, which covers independent artists in Brooklyn. In April 2014, she asked if I would like to shoot for the magazine so I have been working for them since then.”

Kwame’s talent found yet another purpose when he volunteered as a photographer for Walk MS NYC, Bike MS NYC, and the NYC Triathlon. Planning to photograph this year’s Walk MS NYC, Kwame says, “I can’t wait to see what this year brings. It’s great to ask everyone to smile.”

To learn about volunteer opportunities, email michael.providence@nmss.org or call 212-453-3258.

RESEARCH**UNDERSTANDING MS
GENETICS RESEARCH**

BY CLAUDE SCHOFIELD, PH.D., DIRECTOR OF
DISCOVERY RESEARCH AT THE NATIONAL
MS SOCIETY

People affected by MS sometimes ask me: “It’s great that they found another gene that is linked to MS, but what does it mean for me?” Well, the genetics research presented at the annual meeting of the Americas and European Committees for Treatment and Research in MS (ACTRIMS-ECTRIMS), held in Boston this past September, has given me great answers.

HOW GENES INTERACT

Dr. David Hafler (Yale University) one of the founders of the International MS Genetics Consortium, a team that has turned MS genetics on its ear, said, “Virtually every MS geneticist on earth is working together.” He noted that there will likely be hundreds of MS risk genes uncovered eventually.

MAPPING MS SUSCEPTIBILITY

Dr. Philip De Jager (Harvard University), recipient of the 2014 Barancik Prize for Innovation in Research, presented the Consortium’s latest findings that identified 48 new genetic variants associated with MS. De Jager announced that they now have identified more than 159 genetic variations related to MS, and more importantly, have begun to identify the specific immune cells and proteins

involved, and how much weight each one carries.

EXPLORING DIFFERENCES

Dr. Noriko Isobe (University of California, San Francisco) and the Consortium reported on how genes differ between African Americans and Caucasians with MS.

GENES AND VITAMIN D

Dr. Jennifer Graves (University of California, San Francisco) and the Network of Pediatric MS Centers reported on findings of what triggers MS in children. They showed that vitamin D status, which has been linked to MS risk, was associated with MS relapses only if children have a specific immune gene.

TRANSLATING THE DATA

Taking a big step toward translating all of this gene data, Dr. Nikolaos Patsopoulos (Brigham and Women’s Hospital) and colleagues from a range of institutions in Boston examined which proteins interact with the 159 genes that have been pinpointed by the Consortium, and identified more than 2,000 possible therapeutic interactions.

Genetics research is a huge part of our efforts to end MS forever because by understanding factors that may cause MS, we’re better able to target research of solutions to those specific factors. This meeting has given me a lot of hope that we are on the right path to doing just that.

Full article published at
www.MSconnection.org/blog

ADVOCACY

BECOME A DISTRICT ACTIVIST LEADER

The chapter is looking for activists interested in serving as District Activist Leaders. District Activist Leaders are essential in building a local presence and developing an effective grassroots movement, so that when legislation or policy issues are being discussed that impact the MS population, elected officials will turn to the Society as a trusted source for information.

If you are interested in participating, or would like additional information on this important volunteer position, email eugene.veigl@nmss.org or call 212-453-3238. This is a great way to move our legislative agenda forward.

COMMUNITY RESOURCES

ACCESS TO CARE

The National MS Society believes that people living with MS receive optimal care and support when strong collaborative relationships exist between health care professionals and the Society. The Society's Partners in MS Care program is focused on promoting this important mission.

Developed to positively impact the quality of MS Care throughout the country, the Partners in MS

Care program includes healthcare professionals in the areas of neurology, mental health and rehabilitation, as well as sites that provide multi-disciplinary healthcare called Centers for Comprehensive MS Care. The program is designed to recognize healthcare professionals who demonstrate knowledge and experience in MS Care, have a special interest in treating people living with MS, and have shown continuing involvement in the MS community and in National MS Society activities.

Each chapter of the National MS Society identifies healthcare professionals in their area who meet specific criteria set out by the Society. Once reviewed and approved, each chapter and new partner decides how best to utilize their relationship to enhance care to individuals with MS. Possible partnership goals can include: collaborative programs, sharing of resources and information, encouraging opportunities for increased MS training and research, easing referrals for needed services and care for families living with MS.

The chapter currently has active agreements with nine Centers for Comprehensive MS Care, two neurological practices, four rehabilitation practitioners and six mental health practitioners. The chapter is actively engaged in pursuing additional partnerships in all four clinical practice areas, particularly focusing on professionals in locations that are underserved. Individuals with MS who want to locate these recognized providers can call the chapter at 1-800-344-4867, visit the Society webpage at <http://www.nationalmssociety.org> and in the

drop down menu, choose Treating MS/Find an MS Care Provider, or review the following list:

Centers for Comprehensive MS Care

- Alpha Neurology Multiple Sclerosis Center of Staten Island/ Staten Island University Hospital MS Clinic
- Bronx-Lebanon Hospital/Bronx Care MS Clinic
- Columbia University Multiple Sclerosis Clinical Care and Research Center
- Corinne Goldsmith Dickinson Center for Multiple Sclerosis at Mount Sinai Medical Center
- Judith Jaffe Multiple Sclerosis Center at NY Presbyterian Hospital-Cornell
- Linda Morgante MS Care Center at Maimonides Medical Center
- Nyack Hospital-Weill Cornell Multiple Sclerosis Center
- NYU Langone Medical Center MS Comprehensive Care Center
- White Plains Medical Center MS Center at Rye Brook

Neurologic Practice

- Dr. Nada Abou-Fayssal, Lutheran Multiple Sclerosis Center
- Dr. David Jaeger, Crystal Run Healthcare

Rehabilitation Practitioners

- Marissa A. Barrera, MS, MPhil, MSCS, CCC-SLP. Aspire Center for Health and Wellness
- Robert Schreyer, PT, DPT, NCS, MSCS, CSCS, Aspire Center for Health and Wellness
- Emil Euparadorn, PT, DSc, OCS, MSCS, CMPT, COMT, CSCS, Aspire Center for Health and Wellness
- Herb Karpatkin, PT, DSc, NCS, MSCS

Mental Health Practitioners

- Jennifer Finkel, MD
- Tamara Greeley, LCSW, MPA
- Ronnie Hochberg, MS, LMHC, CRC
- Luydmila Jovine, LCSW, BCD
- Deborah Mandelbaum, LCSW
- Gayle Lewis, PhD

EN ESPAÑOL

EL IMPACTO QUE OCASIONA LA ESCLEROSIS MÚLTIPLE EN LA FAMILIA

POR: DRA. MARIA REYES-VELARDE

Cuando hablamos de las personas que viven con esclerosis múltiple (EM) nos referimos a la persona que tiene la enfermedad y a aquellas que están en su entorno día a día. Es muy probable que la familia no tenga un frente común, un proceso coherente y fluido para lidiar con la enfermedad. A menudo el frente está lleno de conflictos donde se reflejan los sentimientos, las actitudes, las necesidades y las prioridades de cada una de las personas involucradas. Según progrese o se manifieste la enfermedad este frente cambiará ya que cada miembro de la familia sentirá y le afectará la EM de una manera diferente. Le afectará porque la enfermedad obliga al individuo que la padece a realizar cambios en sus activi-

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dades y responsabilidades obligando a las personas a redefinir su papel en la familia

¿Cómo puede un familiar o amigo mitigar el impacto de la EM?

- Aprenda más sobre la EM.

Mientras más sepa, más fácil le será comprender a la persona que tiene EM y ayudar a la familia con los cambios.

- Pregunte a la persona con EM cómo le puede ayudar.

No asuma que la persona requerirá la misma ayuda todo el tiempo. Sus necesidades cambiarán según se manifieste la enfermedad. Siempre pregunte, no asuma.

- No compadezca a la persona con la enfermedad o fomente este sentimiento en la familia.

El “pobrecito(a)” o “ay bendito” no tiene lugar en la familia que desea ayudar a la persona con EM a llevar una vida plena. Es importante que los familiares continúen incluyéndole en las actividades sociales aunque la persona no vaya la mayoría de las veces. Es mejor preguntarle a la persona qué puede hacer para que la próxima vez le sea más fácil participar en la reunión.

- Hable con otras personas sobre la enfermedad.

Pregunte a sus doctores, enfermeras o proveedores en salud acerca de la enfermedad. Únase a grupos de apoyo o sea voluntario con la Sociedad Nacional de Esclerosis Múltiple. Si no conoce donde está la oficina más cercana a Ud. llame al 1-800-344-4867 o vaya a www.nationalMSSociety.org. Participar en grupos de apoyo o ser voluntario le ayudará a compartir experiencias y a aprender de otras personas que viven con la enfermedad.

¿Cómo puede ayudar la persona con EM a la familia y amigos?

- Aprenda a decir lo que le pasa.
- Dígales lo que siente.
- Eduque a su familia sobre la enfermedad.
- No abandone sus actividades sociales o deportivas favoritas.
- De ser necesario, busque apoyo fuera de la familia.

Recursos disponibles a miembros de la familia hispana:

Café con Leche es un grupo de apoyo de la Sociedad que se reúne mensualmente por teléfono bajo la dirección de un profesional para todos los hispanohablantes afectados por la esclerosis múltiple y que quieren comunicarse con otros. Para averiguar más o inscribirse, llame al 1-800-344-4867, opción 3.

La experiencia hispana/latina con EM en el internet es un grupo en el www.MSConnection.org para que las personas de descendencia hispana puedan conectar y compartir sus experiencias. Les invitamos a unirse, compartir y hacer conexiones. Visite MSconnection.org/Hispanicgroup hoy mismo.

RECEIVE MSCONNECTION THROUGH EMAIL

If you would like to receive *MSConnection* by email only, please email daphne.mack@nmss.org.

PROGRAMS AND SERVICES CALENDAR

MAY - JULY 2015

Unless indicated otherwise below, for more information and to register call 1-800-344-4867, option 1 or visit www.MSnyc.org.

SUPPORT GROUPS

Ongoing through June

The chapter offers support groups for individuals living with MS, their families and caregivers. More than 50 in-person and conference call groups are organized on a variety of topics. Visit supportgroups.MSnyc.org for more information.

RECREATION & WELLNESS PROGRAMS

Ongoing through June

Programs to promote health and wellness for people living with MS. Visit Recreation & Wellness Programs at www.MSnyc.org.

SELF-HELP GROUPS

Ongoing self-help groups, run by trained volunteers for people living with MS in the five boroughs and in Westchester, Rockland, Orange and Putnam counties. For listings visit Groups and Discussions and click on "Find a Group".

PEER CONNECTIONS

Through the Peer Connections program you can search for and connect with a peer support volunteer who has "been there" and can provide you with helpful tips, suggestions and emotional support for the challenges that MS presents. Visit www.MSConnection.org to learn more.

ACCESS THE APPLE

A community excursion program where you will experience NYC firsthand, regardless of your mobility status. Trips are scheduled to museums, sporting events and more.

MAY

JOB READINESS

Maximize Your Job Search Efforts
NYC–Southern New York Chapter
733 Third Ave., 3rd Fl. New York, NY 10017

*This program also available in the White Plains office

Resume Clinic I: May 5, 1-3 p.m.

*Know Your Rights: May 7, 2-4 p.m.

Resume Clinic II: May 12, 1-3 p.m.

Interviewing Tips: May 14, 2-4 p.m.

Managing MS on the Job: May 28, 2-4 p.m.

LEGAL DAY

Free half hour legal consultations, in person or by phone on topics such as Social Security Disability, Medicaid, Wills/Trusts/Estates, Bankruptcy, Matrimonial Law, Job/Housing Discrimination, General Financial Planning.

TELECONFERENCE: SEX ED FOR GROWN-UPS – INTIMACY IN MS

Featuring Dr. Timothy Hlavinka of Urology San Antonio

May 19, 2015, 7-8 p.m.

May 21, 2015, 10-11 p.m.

JUNE SPRING FLING

A fun-filled evening of dining and dancing.

JOIN THE MOVEMENT: www.MSnyc.org

JOB READINESS

Maximize Your Job Search Efforts
NYC–Southern New York Chapter
733 Third Ave., Third Fl.
New York, NY 10017

*This program also available in the
White Plains office

*What Employers Want: Tuesday, June 2, 2-4 p.m.
Interview Clinic: Thursday, June 4, 2-4 p.m.

MOVING FORWARD

Saturday, June 13, 2015
9:30 a.m. – 3 p.m.
New York Law School
185 W. Broadway, New York, NY 10013

This program is specifically designed for
people newly diagnosed with MS within
the last three years.

JUST FOR KIDS-PROGRAM FOR CHILDREN WHOSE LOVED ONE LIVES WITH MS

June 7, 2015, 11:30 a.m. - 4 p.m.
Chelsea Piers Sky Rink
Pier 61, W. 23rd St. & Westside Hwy.
New York, NY 10011

A day of fun and learning for children ages 6 - 16
who have a parent or relative living with MS.
Registration details will be available April 15, 2015.

JULY

TELECONFERENCE: GENDER DIFFERENCES IN MS

Featuring Dr. Barbara Giesser of UCLA
July 21, 7-8 p.m.
July 23, 10-11 p.m.



33rd Annual Race Against MS

Thursday, June 18, 2015
at
Belmont Park Race Track
Turf & Field Club

Presented by:

Structure Tone Inc.
Atlas Acon/ New York
Electrical Power Services
Vornado Realty Trust

To reserve your spot today,
please call: 212.453.3235 or
email Gina.Nicoletti@nmss.org

LIST OF DONORS THANK YOU FOR MAKING A DIFFERENCE

Relying on the support of caring individuals, businesses and foundations, listed below, the New York City – Southern New York Chapter strives to address the challenges facing all those who are affected by this life-long disease. Your commitment and personal dedication helps the 12,000 people living with MS in the five boroughs, Westchester, Rockland, Putnam, Sullivan and Orange counties and gives us the tools necessary to create a world free of MS. Contact Shannon Mastroianni at shannon.mastroianni@nmss.org or call 212-453-3241 for more information.

We wish there was space to thank all of our generous donors. Regardless of your gift's size, it is invaluable and tremendously appreciated. The gifts listed here represent the generous support of individuals, corporations and foundations contributing \$500 and above during the period of October 1, - December 31, 2014.

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