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LETTER FROM THE CHAPTER PRESIDENT

JIM ROBERTS

What A Year It's Been So Far

Greetings to all our friends throughout the National MS Society! What an exciting and productive year it has been at the New Jersey Metro Chapter! We are three quarters through our fiscal year, and it’s hard to believe all the exciting things that have occurred at the chapter to date.

Four major events have already been held and are enjoying success since our last newsletter. Walk MS, MS Spring Golf Classic, Bike MS Coast the Coast and MuckFest MS. All enjoyed great turnouts and have and/or will raise significant funds to support our research, programs and services, etc. Our MuckFest MS event, held on June 21, completely sold out with 4,000 participants a full week before the event - a first for our Chapter.

Coming up this summer is our new MS Summer Golf Classic on Monday, July 21 at the majestic Hollywood Golf Club in Deal, NJ. So break out those clubs, take a one-day vacation, and join us on one of the state’s finest golf courses! September continues our busy events season with two Bike MS events: Hops to Hops on September 14 in Lambertville and Country Challenge on September 20 and 21 in Morristown. If you prefer to support the Society through the arts or a culinary experience, then join us at Musical Moments for MS featuring the talents of Patti LuPone on September 17 at the NJPAC in Newark or at our Forks & Corks White House Dinner on September 27 at the beautiful Forsgate Country Club in Monroe Township.

We have also been busy with our programs and services throughout the year as well, delivering wellness programs, self-help group sessions, nursing home outreach, housing initiatives and, of course, our Computer Outreach Program, which continues to gain in popularity. Our programs and services have had an impact on thousands of people affected by MS, and our team of professionals stand ready to assist you when needed.

Please join us at the myriad of fundraising events or programs offered by the chapter. Whether it is as a volunteer or a participant, we stand ready to ensure your experience with us is second to none! Enjoy the summer, and I look forward to seeing you at one of our events or programs!

Jim Roberts
Chapter President
New Jersey Metro Chapter

Please note our new mailing address!
Aspen Corporate Park 1
1480 U.S. Highway 9 North
Suite 301
Woodbridge, NJ 07095

Board Leadership:
Chair
Bonnie Higgins
Immediate Past Chair
Michael D. Gibney
Treasurer
Joe Welter
Secretary
Michael Pawelczak

Staff Leadership:
Chapter President
Jim Roberts
Executive Vice President of Development
Karen Drzik
Vice President of Programs & Services
Nancy Chazen
Vice President of Finance
Gwen Leach

The National MS Society, NJ Metro Chapter and the MS Centers in NJ have collaborative relationships that enhance the services that are provided to people and their families who live with a diagnosis of MS. The MS Centers provide clinical care and medical expertise while the Chapter complements that care by offering a variety of educational and support services. The five MS Centers in NJ are listed below:

Bergen County
The MS Comprehensive Care Center at Holy Name Hospital
718 Teaneck Road, Teaneck, NJ
201-837-0727
http://www.holynamemgroup.org/MSCenter/

Essex County
MS Comprehensive Care Center at Barnabas Ambulatory Care Center
200 South Orange Ave, Livingston, NJ
973-322-7484
http://www.barnabashealth.org/hospitals/ambulatorycarecenter/programs/ms/

Rutgers-NJMS Multiple Sclerosis Center
90 Bergen St, Suite 8100, Newark, NJ
973-972-2550
http://njms.rutgers.edu/departments/neuroscience/clinical_program_patient_care.cfm

Middlesex County
Rutgers-Robert Wood Johnson Center for MS
125 Paterson St, New Brunswick, NJ
732-235-7733
http://umns.rut.edu/public/clinical_services/program.aspx?dept=neurology&program=ms

Monmouth County
The Linda E Cardinale MS Center at CentraState Hospital
Star and Barry Tobias Ambulatory Campus
901 Main St., Freehold, NJ
732-294-2505
http://www.centraheal.com/Multiple-Sclerosis-Center

Information provided by the Society is based upon professional advice, published experience and expert opinion. Information provided in response to questions does not constitute therapeutic recommendations or prescriptions. The National Multiple Sclerosis Society recommends that all questions and information be discussed with a personal physician.

The Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered valuable information. The Society assumes no liability for the use or contents of any product or service mentioned.

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New Jersey Metro Chapter
COMPUTER OUTREACH PROGRAM

The Chapter’s Computer Outreach Program (COP) is designed for people with MS who are isolated; it helps them to connect with family, friends and social networks. It has become a popular program within the National MS Society.

The COP is supported by donations from the community, allowing the Chapter to distribute computers (and related equipment) to qualified people with MS in NJ and other states throughout the northeast. One constant and dedicated donor to the program is Mr. Robert Giaquinto, known as “Gio” to his friends. Gio has supported the National MS Society for nearly 35 years. Last year he supplied the region with 40 computers and tablets!

Chapter President Jim Roberts thanks Gio for his generous support, recognizing his generosity to the NMSS; Mr. Giaquinto has never missed a year of making a donation to the National MS Society for over 35 years. He has most recently been a benefactor of our dynamic Computer Outreach Program, which provides computers to our friends living with MS, a program which has been recognized nationally for its success.

NEW RESIDENT OF MONTVALE, NJ

MEET BARBARA BRAVE, ONE OF THE NEWEST RESIDENTS OF MONTVALE, NJ!

Barbara has lived with MS for thirty years. Although she lost some mobility to MS, she didn’t lose her enthusiasm for life! After 13 years of living in a long term care facility where she received quality care, she yearned for a place of her own where she could live independently with appropriate support from a variety of state and community agencies. She learned of the different housing initiatives that were highlighted by the National MS Society, NJ Metro Chapter and applied for residency. Good news came her way when she was notified of approval for an affordable and accessible apartment in the new complex, Montvale Commons in Montvale, NJ.

Barbara moved in to her new apartment in May. She is busy making friends and learning about her community. She maintains communication with her friends and supporters at her old long term care facility as she volunteers there twice a week! Congratulations to Barbara and her new friends in Montvale!
“MEET AND GREET” AND SO MUCH MORE AT CHAPTER SELF-HELP GROUPS

The Chapter has more than 30 self-help groups in its 14 county service area. These groups bring together people who share a common life experience for support, education, and mutual aid. Members of self-help groups share a belief that positive personal change happens through individual efforts with the support of others. Everyone is welcome.

Many groups take time off in the summer but are energized again in September!

Think about connecting with a group that is convenient to you. For a complete list of self-help groups, contact Lisa at the Chapter at lisa.torre-janssen@nmss.org or at 732-508-4431.

DO YOU HAVE A QUESTION ABOUT EMPLOYMENT?

Do you have an employment question you would like answered? Are you curious about workplace disclosure, social security benefits, need a reasonable accommodation or are you thinking about returning to work?

If so, the National MS Society has a dedicated employment specialist to answer your questions. Feel free to pose your questions directly to this email address: EmploymentQuestions@nmss.org. You can expect to receive a response within 48 hours.

SWIM-IN LUNCHEON

At a recent luncheon, Swim-In celebrated another successful year of therapeutic swim. Swim-In is a community-based project and is co-sponsored and funded by the Bergen County Section of National Council of Jewish Women and the National Multiple Sclerosis Society, NJ Metro Chapter.

INSPIRATION BY THE SEA

Participants enjoying a special program in April, Inspiration by the Sea, funded by the Ocean First Foundation.
RESEARCH OPPORTUNITIES

Do you want to participate in a research project? If so, there are several in NJ that may interest you:

THIS STUDY IS TESTING THE SAFETY AND EFFECTIVENESS OF AN INVESTIGATIONAL DRUG IN REDUCING MS RELAPSES, FUNDED BY NOVARTIS.

If you or someone you know has been diagnosed with relapsing-remitting multiple sclerosis (RRMS), you may be interested in a medical research study that is taking place at Rutgers-New Jersey Medical School (Newark).

To pre-qualify for this study, you must:

• Be between the ages of 18 and 65
• Have RRMS and 1 documented relapse during the previous year or 2 documented relapses during the previous 2 years

The study doctor will assess additional criteria during the screening period to determine whether this study is suitable for you. There is no expense to participate in this study. Eligible participants will receive study-related care and evaluations at no cost. Your participation is completely voluntary.

To find out more about this research study and learn if you pre-qualify to participate, call Deb Thurston at 973-972-2324.

MEDICATION BELIEFS IN MS

Do you have relapsing-remitting MS? Do you choose not to take medication to prevent flare-ups? If so, researchers at the Kessler Foundation Research Center are looking for you! You are NOT required to take disease modifying treatments to be part of this study. Instead, we are interested to learn your reactions to telephone counseling you will receive.

It is hoped that this research will help us improve MS care and better understand reasons some patients with MS choose not to take medication. All participants will undergo a baseline evaluation consisting of pencil-and-paper tests and questionnaires lasting approximately 1½ hours. Following this, you will complete five 20 minute telephone conversations about MS medications. Finally, you will be asked to complete additional questionnaires at home at the completion of the study. You will be compensated $200 for your time. To be eligible, participants must: (1) be diagnosed with a relapsing form of MS; and (2) have discontinued taking a disease modifying medication. If you are interested in participating in this study and meet the above criteria, please contact Lauren Strober, Ph.D. at 973-324-8459 or lstrober@kesslerfoundation.org OR Juliane Armstrong, B.S. at 973-324-8457 or jarmstong@kesslerfoundation.org.

HELP DEFINE THE FACTORS ASSOCIATED WITH EMPLOYMENT AND MS

Researchers at the Kessler Foundation Research Center are interested in learning more about the factors associated with maintaining employment in MS. Individuals who are gainfully employed and/or considering leaving the workforce or needing to cut back on hours are eligible to participate. All participants will complete an evaluation consisting of self-report questionnaires and two paper-and-pencil tasks. Questionnaires can be completed either in person or online. All participants will
be compensated for their time. To be eligible, participants must be: (1) between the ages of 20 to 64; (2) diagnosed with definite MS; and (3) have no other neurological illness. If you are interested in participating in this study and meet the above criteria, please contact Lauren Strober, Ph.D. at 973-324-8459 or lstrober@kesslerfoundation.org. You can read more about research at Kessler from this link: http://kesslerfoundation.org/researchcenter/n&n/researchstudies.

For more information about how you can participate in research studies, click on the National MS Society link: http://www.nationalmssociety.org/Research/Participate-in-Research-Studies/Surveys#section-25

MAKING LIFE MORE ACCESSIBLE

After a long search in the Hunterdon County rental market, in February 2014 Hope found suitable housing with 3 bedrooms for her and her 5 year old daughter and her mother. As the 3 generations of the family settled into the apartment, it became obvious that the stairs were going to be difficult for her mother whose MS was progressing. Hope reached out to the Chapter for guidance in making her mother's daily activities much easier. After much discussion, she realized that a stair lift would be of great assistance to Wanda (Hope's mother) as she navigated to and from the 2nd floor of an apartment in the two family home. With little financial support, Hope and Wanda didn't think it was possible to get a stair lift installed in their residence, a solution that would cost over five thousand dollars.

At the same time that Hope was looking for information about a stairlift, the Chapter received a call from Dennis Gaynor, a representative of Handi-Lift, a provider of accessibility equipment for homes and commercial buildings in New Jersey and New York. Handi-Lift's mission of accessibility with dignity has been guiding the company since 1975. Dennis explained that Handi-Lift wanted to give back to the community by helping a family in need by furnishing and installing a well-deserved Stannah stairlift.

The Chapter was happy to bring these parties together to make life easier for Wanda. Hope and Wanda are thrilled! Wanda says, “We are forever thankful for making such a huge impact on our lives. “ Hope continues, “This was a huge struggle for my mom, and now she can move freely up and down the stairs.”

Handi-Lift is grateful to the Chapter for identifying an appropriate person with an immediate need for a stairlift. James Boydston, the owner of Handi-Lift explained that, “Once the connection was made with a user in need, everything just worked out so smoothly. It was such a blessing to see the smile on Wanda’s face upon her taking the first ride up the stairs.” The entire process took less than a month to accomplish. After communicating a vision of assisting a NMSS client, the home was surveyed, the stairs were measured, the lift was ordered, and in one morning it was installed and handed over to Wanda. A great ending for all involved!
MEET A SCHOLAR

Kyle Maccia is a student living his best life with MS! The Chapter is proud to feature Kyle as a recipient of a Chapter scholarship. Kyle is entering his senior year at Temple University in Philadelphia, majoring in Finance. He has been chosen for an internship this summer with the Defense Logistics Agency Troop Support (a Naval Support Activity), located in Northeast Philadelphia.

Kyle and his family have had a Walk MS team since he was diagnosed with MS eight years ago; for the first time Kyle participated in Muckfest MS in June!

This year the Chapter distributed a total of $47,550, due to the amazing generosity of many donors, specifically a significant grant from MS Hope For A Cure, The Litterman Family Foundation and the Michael Scrocca Memorial Fund. We are also thankful for the ongoing guidance provided by our long-time Board and Scholarship Committee member Meryl Ravitz. Congratulations to Kyle and all of our 53 Scholarship Awardees. We wish them all the very best!

2014 SCHOLARSHIP RECEPTION

Scholarship recipients with Chapter Board members and staff at the 2014 Scholarship Reception.

WELLNESS CLASSES WILL RESUME IN THE FALL

The Chapter offers a variety of Wellness programs throughout New Jersey to Clients & Caregivers – classes will resume this fall! The calendar will be available in early August and registration will begin at that time.

Our Wellness classes include Yoga and Tai Chi, which are modified so that individuals may perform the movements in a seated or standing position, and an Aquatics class that has a chair lift.

Clients may bring a companion or aide to any of the classes, so that together, they can enjoy the benefits of exercise. Our thanks to The Peter Jay Sharp Foundation, for providing funding for the Chapter’s Wellness programs.
DAY OUT PROGRAM

Thanks to specific funding from the Chapter, Sharon, who is a resident of a long term care facility, was able to attend her son’s high school graduation in June. Sharon is posing with her two children Sabrina and Robert. This is a good example of how the Chapter uses your fundraising dollars!

CONNECT WITH OTHERS ON MSconnection.org

Social networking has become one of the most popular ways to connect online. But although public social networks may offer an exciting opportunity for connections, they can also carry risks to personal privacy and medical history – particularly for people living with a chronic health condition like MS. That’s why the National MS Society created MSconnection.org, a social networking website and online community for people living with MS, their loved ones and experts to connect in a safe and secure environment.

Join thousands of people supporting one another and exploring the issues that shape your world. All you need to do is sign up and create a profile to start connecting.

- Connect with other community members based on symptoms, treatment, geography, interests and more.
- Search for and contribute to discussions about the issues that shape your world. Provide and receive support, information, and advice related to the topics that shape your world.
- Join groups to connect with people who share your same interests, challenges and hopes. Groups may focus on support, advocacy, education, or be more social in nature.

Read the MS Connection blog to learn from people living with MS, those who care about them and MS experts on a wide range of topics.

ATTENTION VETERANS!

People who served in the armed forces may have special benefits that address their MS related needs. For more information to see if you are eligible for specific veteran programs, contact Joyce Williams at 973-676-1000, ext. 1729.
NEW ADVOCACY MANAGER ANNOUNCED

The National MS Society is pleased to announce that Mara Brough has been selected as the new Senior Manager of Advocacy for Pennsylvania and New Jersey.

Before joining the Society, Brough served as Congressman Patrick Meehan’s District Representative and Office Manager. Her many duties for the congressman included casework with constituents who needed help with federal agencies, many of whom live with MS.

“People would turn to us when they were having problems with Medicare coverage or were denied Social Security Disability Insurance,” Brough explains. “I was really surprised at how much we could help people by guiding them through the system and advocating on their behalf.”

Now Brough is looking forward to bringing her expertise to the MS Society so she can work on behalf of people living with MS on a full time basis. “Once you start working with people affected by MS, it’s shocking how different the disease can be for each person,” she says. “Plus, with MS you never really know what’s going to happen next.”

In addition to knowing the ins and outs of federal programs such as Medicare and Social Security, Brough is also well versed in the Affordable Care Act – in fact, she was tasked with training her colleagues in the constituent office on the salient points of the legislation.

A resident of Springfield, PA, Brough is a graduate of Kutztown University who is currently working on her master’s degree in public administration at West Chester University. Brough explains that she chose to study public administration because she wanted to help people – something she is very excited to do at the National MS Society.

“The MS Society is extremely well-respected and is truly on the cutting edge,” Brough notes. “It’s an organization that leads the way for other non-profits in how it fundraises and conducts advocacy on behalf of its members.”
BIKE MS: TIME TO CHALLENGE YOURSELF AND YOUR FAMILY AND FRIENDS
WE NEED YOU TO RIDE, VOLUNTEER OR INSPIRE OTHERS TO JOIN US!

Come be a Part of NJ Metro Chapter’s Cycling Series!

The NJ Metro Chapter is proud to host 3 cycling events each year. In May we held Bike MS: Coast the Coast in which 1,600 cyclists participated. Those who rode had a choice of 25, 50, 85, 100 or 170 miles! The 170 mile route travels the Jersey Shore from West Long Branch to Cape May. This year’s event was particularly glorious as there were sunny skies all weekend. Thank you to those who pedaled the miles or joined us as a volunteer. We know our event was brighter and warmer thanks to your support!!

This coming September we will again host Bike MS: Hops to Hops on Sunday, September 14th and Bike MS: Country Challenge on the weekend of September 20th and 21st. There are ride lengths offered for the beginner and casual cyclists and longer routes for more experienced cyclists. With many friends and families participating, these events are exciting and fun! Virtual rider registration is an option so that all chapter members can participate, inspire and encourage others to ride for them or with them. Please consider joining us as a cyclist or a volunteer. Invite friends and family to ride with you or to ride on your behalf!

Whatever ride length you choose, our Bike MS events are fully supported with rest stops every 10-12 miles, snacks, SAG vehicles, medical assistance, mechanical support and return transportation. We finish our rides with barbecue lunches and hot dinners for a fantastic celebration with family and friends. All you need is the passion to pedal for a great destination: A world free of MS!

Volunteers are a key to the success of this event. There are volunteer positions at event check-in, rest stops, entertainment, photographers and finish lines. We need you to help us keep our Bike MS events exciting and fun!

Please help us make this event a success! Register on-line as a participant or a volunteer at: bikenjm.nationalmssociety.org or call us at 732-660-1005.
MORE THAN 11,000 PARTICIPATED IN WALK MS 2014!

Although wind was definitely present, the sun was shining bright as a sea of orange stormed northern and central New Jersey for Walk MS on Sunday, April 27th. Both Walk MS participants and volunteers joined forces to raise money for those living with MS, celebrate 25 years of Walk MS, and, most importantly, help us reach our goal of $1.8 million! To date we have raised more than $1.6 million and are moving closer toward a cure with every dollar!

From Liberty State Park in Jersey City, all the way down the Garden State Parkway to Seaside, more than 11,000 participants shared the same goal as they walked or ran – to END MS FOREVER! Families, coworkers, community clubs, and friends connected together – some wearing handmade team t-shirts, tutus, or eye-catching headbands – and joined forces to raise money and awareness. And, our teams came out ready to fight for our coveted awards like Most Team Spirit, Best Dressed Team, and Rookie Team of the Year!

Our Lincroft and Ridgefield Park locations also hosted 5K runs for anyone looking for an extra challenge. Our 5K run in Ridgefield Park was Grand Prix Certified and offered runners the opportunity to compete for awards within their age bracket and top finisher overall. And, Toufayan Bakery graciously provided breakfast to all runners, giving them the perfect boost to stay and participate in Walk MS!

We attribute the success of Walk MS to our inspiring and motivating Team Captains, exceptional and supportive team members, devoted individual and virtual walkers, energetic and enthusiastic volunteers, incredibly generous sponsors and dedicated staff. The board and staff of the New Jersey Metro Chapter cannot thank everyone enough for their contribution to the success of our 25th anniversary of Walk MS!

Also contributing to the outstanding success
of this event are our wonderful sponsors. Our sincere appreciation to our Presenting Sponsor: Novartis. Additionally, a big thank-you to Toufayan Bakery, lunch sponsor for all 12 Walk MS sites! And, our heartfelt thanks to our community-minded companies:

Foodtown, Walgreens, Sam’s Club, Bayer HealthCare Pharmaceuticals, Johnny On The Spot, Acorda Therapeutics, CentraState Healthcare Foundation, Genzyme, EMD Serono, Enterprise Holdings, Questcor, Biogen, Genentech, Meridian Neuroscience, Dr. Richard Richter, Shore Rehabilitation, Teva, The Luminations Group, NJ Manufacturers, Current Rehab, Hackensack University Medical Center, and Flemington Car & Truck Company. We are also truly grateful to our awesome media sponsors for their efforts and support of this event: WRAT Radio, Magic 100.1, WDHA 105.5, WTNR, and WGHT. A big thank you to our amazing rest stop sponsors: Summit Medical Group, Whole Foods Market, RoNetco Shop Rite, Shop Rite of Hunterdon County, Circle Hyundai, and Alexander's Teas. Finally, our heartfelt appreciation to Bar Anticipation and Crystal Geyser. We thank all of you for your invaluable support!

A key component to our Walk MS success is due to dedicated Site Coordinators! These extraordinary individuals (and their families!) work tirelessly each year to ensure their walk sites run smoothly for all participants. Our heartfelt appreciation to: Tom and Christine Crowell (Seaside), Bob and Jean O’Connor (Freehold), Kathy DeFillippo (Roxbury), Claudia Marchese (Flemington), Maria and Joe Avena (Hamilton), and Giovanna Branciforte (North Brunswick). Words cannot express our gratitude to you for all that you do!

Funds raised by Walk MS go toward funding cutting-edge research and supporting hundreds of educational and social programs and services for the more than 10,000 individuals and their families in our Chapter region who live with MS every day. Congratulations and thank you again to everyone involved in this event. Thank you for helping us achieve our mission to create a World Free of MS and for making a difference in the lives of our loved ones and friends living with MS. Together, we will STOP (Progression of this Disease), RESTORE (What’s Been Lost) and END MS FOREVER!
BERGEN COUNTY FAIR & HARVEST FESTIVAL MAKES DONATION TO NMSS NEW JERSEY METRO CHAPTER

Recently, Director of Teams & Special Projects, Alexis Stone (pictured below at far left) and Executive Vice President of Development, Karen Drzik (pictured below, second from left) were honored to accept a donation made by the Bergen County Fair & Harvest Festival. The check was presented by Bergen County Executive, Kathleen Donovan (pictured center) and Leonard Hennig, Commander, Teaneck VFW 1429 (pictured at far right) along with his wife Kathy (pictured to Leonard’s left).

NJ METRO CHAPTER CALENDAR OF EVENTS

Summer Golf
July 21, 2014
www.nationalMSsociety.org/NJM

Challenge Walk
September 5-7, 2014
www.nationalMSsociety.org/NJM

Bike MS: Hops to Hops
September 14, 2014
bikenjm.nationalMSsociety.org

Musical Moments
September 17, 2014
www.nationalMSsociety.org/NJM

Bike MS: Country Challenge
September 20 & 21, 2014
bikenjm.nationalMSsociety.org

Forks & Corks: A White House Dinner
September 27, 2014
www.nationalMSsociety.org/NJM

Women on the Move Luncheon
November 14, 2014
www.nationalMSsociety.org/NJM

Climb to the Top
November 15, 2014
eventnjm.nationalMSsociety.org
SAVE THE DATE!
September, 27, 2014

The evening will begin with champagne and hors d’oeuvres (cash bar also available) and then, guests will enjoy a three course dinner.

Each course is one that was served at a White House dinner and a favorite of one or more of the administrations. Former White House Chefs Guy Mitchell and Woody Raber will prepare each White House recipes as they:

- Answer questions
- Share presidential protocol for food preparation
- Share stories, including the most unusual menu requests

Every year, the White House hosts many dinners, each honoring an individual or group of individuals. And so, the dignitaries at our White House dinner are those living with multiple sclerosis. Each of our dignitaries will receive a “ribbon of hope” upon entering and will receive Presidential treatment throughout the evening.

We hope you will join us for a memorable evening!

For more information please contact:

Karen Drzik:
Executive Vice President
201-977-6054
Karen.Drzik@nmss.org

Allison Apuzzo:
Special Events Coordinator
732-508-4428
Allison.Apuzzo@nmss.org
CHALLENGE WALK MS: CAPE COD SEPTEMBER 5-7 2014

3 DAYS. 50 MILES. CONNECT TO END MULTIPLE SCLEROSIS

REGISTER NOW: challengewalkMS.org or 1.800.344.4867